I Left My Voice On The Dining Room Table

Surviving Throat Cancer and Talking About It

Pat Wertz Sanders

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Disclaimer

This book is a personal memoir reflecting the author's experiences and understanding at the time of writing in 2014. It is not intended as medical advice. Medical knowledge, treatments, and best practices evolve over time. Please consult qualified healthcare professionals for current medical guidance.

Dedication

Dedicated to Dutch Helms and the many WebWhispers.org volunteers who have offered advice and services to help laryngectomees have better lives.

To Dutch, our friend, founder, and leader:
Assignment accepted. Mission Accomplished.
WebWhispers Executive Committee

Preface

I was hurrying to be sure I had what I needed to take to my massage appointment with Shari. I put everything I needed on the table in the dining room.

After stopping to answer the telephone, I glanced at the time and realized I'd better get moving. Thirty minutes later, I parked the car, right on time, and reached for my shoulder bag.

The side pocket where I always carried my Servox —my electronic larynx, my voice—was empty and I had a feeling of pure panic. It was the first time this had happened. That device was my only way of making a sound since my laryngectomy, and I was totally mute without it.

My brain was spinning as I tried to think what I would do if anyone stopped me to talk or ask a question. Even worse, I thought of how this could have happened and where I could have lost it. I breathed a sigh of relief when I remembered the telephone call, using the instrument, and putting the Servox back on the corner of the dining room table but not in my bag. With this, I took a pad of paper and wrote a note, which I handed to my friend when I went into her office. It said:

"I left my voice on the dining room table."

Introduction

You're on the way home from the appointment with the surgeon, and he told you that he's going to remove your voice box next week. You won't be able to talk, but he said he's going to do a new thing that will give you a voice before long. If it works right, it would sound a lot like your old voice.

Your wife is driving and you're afraid to say anything or she'll fall apart. What will you say to the kids when they come over later?

There's going to be a lot of crying. Junior, named after you, is too young to understand. How can you tell him you won't be able to teach him to fish? The doctor said there will be no more going out in boats. You can die if you fall in the water with that hole in your neck. Swimming? That's over. He even said to be careful taking a shower. What do you have left to live for?

I'll tell you. Because the scenario above is not the one you have to follow.

I am dedicated to helping those who have had or are facing a laryngectomy. The after effects that everyone dreads are those of immediately losing the ability to speak. Many concentrate on the loss of their original voices, almost to the exclusion of the other changes that may make life more difficult but are not discussed much in those early appointments.

I thought my big life change was January 1994 when my mammogram showed cancer and my treatment plans started. Once treatments were over, having had

breast cancer changed very little about my long-term, everyday life and purpose.

My real challenge had already begun the year before with a bad dry cough. That cough became the throat cancer, discovered only after the breast cancer treatments, and it made a different person of me. It brought out abilities and character of leadership I had never worked to develop up to that point.

I seemed to be led or pulled from one opportunity to learn to another, where I would share the knowledge I gained though living, listening to, and helping others. I learned through writing, editing, research, and experimenting.

I hope this will let you, your family, and friends be more prepared than I was, and to know there is hope for the future.

Chapter One
Voice Treatments, 1993

I never thought I'd be a writer. I was a talker. I could talk my way out of or into just about anything. But cancer was the beginning of something I couldn't talk myself out of. It's how I lost the voice I used to have and found a multitude of other voices.

The voice I used for over sixty years was low, sexy, controlled, and pleasant. I often stopped a room full of people just by raising my voice. As a sales person, I used my voice to make a living, or represented organizations where I was a volunteer on radio and television. I later led discussions and spoke at seminars about all aspects of divorce and single life. I read for the blind at the Radio Reading Center and acted with Seasoned Performers, a group that took plays to schools, churches, and nursing homes. Everything I did was based on being able to speak clearly. Then my voice got very husky and stayed that way. That's when my whole life started changing.

I had been treated in the spring for moderately high blood pressure with an ACE inhibitor, which caused a lingering hacky cough and made me feel as though I had something in my throat so that I cleared my throat constantly.

In Seasoned Performers, I had a part in a play acting as the Mother of Inventions. Our performances were in school gyms or the social rooms of retirement

homes where the acoustics were not the best. Before I would make my entrance each time, I would try to quietly clear my throat of whatever was bothering me. I felt like I would choke up or cough on stage. My voice was getting a grainy sound with no clear bell tones.

I still smoked the five cigarettes that I allowed myself each day. Smoking, drinking, and voice strain were three of the contributing factors toward throat cancer, but I was not aware of the increase in cancer rates for those that combined smoking and drinking or would have a cocktail before supper every night.

A fourth problem was acid reflux. Maybe I had watched too many television ads, because I thought all I had to do was take over-the-counter medications when I had a little indigestion, and the discomfort would come and go. It never occurred to me that every time acid washed up into my throat I was getting tissue damage. Without realizing it, I had put myself in the way of throat cancer as surely as I would have put myself in danger had I stepped out into a busy highway and tried to dodge the cars and trucks.

Sinus infections and bronchitis were regular problems for me, spring and fall, so my hoarseness was not that uncommon. But when it would not clear up even after a change of medication, my doctor sent me to a specialist. My first trip to the ENT was not a “look in the ears, nose, and mouth” that I had become accustomed to in general checkups. When they wheeled in the cart with all of the tubes and gadgets, the nurse explained that she was going to spray something in my nose to deaden it. My nerves went on alert. My nose! What does she mean, my nose? It’s not my nose, it’s my throat!

It was not a mistake. The tube was put up my nose and snaked its way down my throat. It had a light and mirror on the end that enabled the doctor to look around while he rotated it so he could get an idea of what might be causing my hoarseness. I was frightened at this new experience, even though he was gentle and soft spoken and it didn't feel as bad as I thought it would. He said that he would tell me immediately what he found as he saw it, and he began to talk, telling me to try to make certain sounds.

As he looked, he said first, "You do not have cancer." I was very still but he could feel the difference in my tension as my shoulders relaxed. He continued, "There's a nodule on your right vocal cord that's preventing your vocal cords from closing properly."

This was news that made the tube down the nose worthwhile. After he removed the light, he explained that the nodule was similar to a callus and we would try voice rest and a medication for thinning mucus to help prevent coughing. Then we would see if my voice got better. I made an appointment for another visit in three weeks and I started on my first term of relative quiet.

Voice rest means that you talk only when it's necessary and then only so you can be heard up to four feet away, but not across the room. Four feet is closer than you think, and many people are not comfortable that close. One of my friends is a pacer and would be moving the whole time we talked. She would stop at a window and ask me a question as she looked out. Another would select a seat about twelve feet away because that was her comfort zone, while another was hard of hearing. I found

it impossible to be heard so I would put my fingertips against my lips to remind me to nod instead of speaking.

For that to work, you need to get their attention. I found an average rectangular dining table is thirty inches across and was the most comfortable place to sit and visit. It enabled me to speak quietly or use my hands to point and signal in a way that helped me to be more effective with the voice rest. There could be no music, TV, or background noise to compete. With total silence, there was no competition to concentration and it was easier to be understood.

Three weeks later, I was back at the ENT's office for another one of those looks at the vocal cords, and the doctor decided to send me to a voice pathologist. I learned that I was speaking in such a way that my vocal cords would hit together sharply. I started with daily exercises that would teach me to close my vocal cords together gently, with my words less clipped. After several months, my voice did seem greatly improved. The ENT thought he had found the answer, and I thought I was out of the woods.

Chapter Two
Cancer – The First Time Around, 1994

I started 1994 in good spirits, planning a trip to Alaska for the next year, working part-time to pay for my trip, swimming two to three times a week at the Y, watching my diet, taking good care of myself, and being careful that I didn't misuse my still-sensitive voice. I finished my yearly physical and blood tests in January with good reports and went for the final part, a mammogram. A few days later, my doctor recommended a breast biopsy.

I telephoned my son Scott to rant and rave. I was sure I didn't need this. It would be painful and a waste of time. I finally calmed down, accepted the inevitable, and called one of my best friends, trying to avoid crying from frustration of needing a biopsy. This went on, over and over again. I told each friend, and we would talk about the fact that I would need someone to go with me, maybe even overnight.

I did not want to do this biopsy. I cried myself to sleep from exhaustion and frustration, but the next morning I got up ready to make an appointment with the only surgeon I knew. He had performed a biopsy on my other breast eight or nine years before. It had been benign, but had been such an unpleasant and painful experience that it contributed to my fear of another

similar surgery, even though I was absolutely positive this was not cancer. It was an annoyance.

The next morning, I went by to talk with my family doctor. He reminded me that he had treated me for a terribly infected hornet sting in the upper, outer quadrant of my right breast about a year and a half before, and he thought the mammogram might be showing scar tissue from that. We checked his records and it was in the same place as the “new” spot on my mammogram. I felt wonderful, and was convinced this was not going to be serious.

With this in mind, I went to see the surgeon, thinking I would explain all of this and talk him out of the immediate biopsy and into waiting to see what happened on the next mammogram. The surgeon would have no part of that. He showed me the spot that looked like an arrowhead whose back edge was kind of fuzzy. He explained that the uneven edges were not a good sign and we needed to take a look at what was there. He insisted on removing the questionable area. By then, I just wanted to get it over with. I was ready to move on and heal.

The biopsy was actually a lumpectomy, but when the report came back several days later, the tiny tumor was sitting right on the edge of the section removed and it showed invasive lobular carcinoma. I had answered the telephone at my dining room table, my favorite place to have my morning coffee and read the paper, when I heard the doctor's voice. He hated to tell me but the lab reported that the margins or edges of the tissue removed had cancer cells so we would need to go in for a reincision to remove another section from the original

site. Plus, since it was a confirmed carcinoma, I would have another incision under my arm for removal of lymph nodes. All of this tissue would be checked for the spread of cancer cells. I needed to call the surgeon's office the next day to make arrangements to get this done.

I was stunned. With all the fuss about doing what I thought was a useless biopsy, I never believed I had cancer. A few deep breaths later, I reached for the telephone to call my son and when he answered, I couldn't speak... I cleared my throat and barely got the words out, "It's cancer." It was the hardest word I ever had to say, a word that no one used. The Big C became even uglier when it was laid bare.

Once I had that out, I could explain what I had to do and we could discuss it. His wife told me later that when Scott got off of the phone, he walked into the kitchen, and she knew there was something terrible, as he was white as a sheet when he said, “Mom had cancer.”

We didn't know anything about cancer except that people died from it. We heard of the nausea and terrible side effects from chemo. Radiation was a scary word. I was so frightened of what they might do to me that I didn't even cry. I stepped into a world full of unknown monsters, and the next step was worse than the biopsy I had just been through.

I was in the hospital for two nights and did not know when I could go home since I had to wait until the pathology report was in. It held my fate. A good report meant I would be released to go home. A bad one meant the surgeon would want to do a mastectomy and I would

go back to surgery immediately. I was shaking inside while I put on as calm a surface as I could manage. My visitors chatted and I said words I never remembered saying. The longer we waited, the more I imagined the worst. Finally, when the doctor walked in, he said, smiling, “How would you like to go home?” I was dressed and out of there in record time. At least this surgery was averted.

My next major step was to be radiation therapy.

Chapter Three
Breast Radiation, March 1994

The surgeon had his staff set up an appointment for me at the hospital's cancer center, where they would explain the next steps in this process.

The initial examination was simple and the doctor, a radiation oncologist, explained they would be working as a team: doctors, nurses, technicians, and everyone else in the department. I was sent for an x-ray and bone scan, and an appointment was made for me to come back to be measured and have my skin marked for precisely the area they planned to treat. He explained that this would require a long appointment and would be uncomfortable because I would have to lie in one position on a hard table with my arm raised. They would use an indelible pen to draw the marks since they would have to remain there for the duration of the radiation treatment.

I had heard people talk of having so many weeks of radiation, but I had no idea that it was every weekday. They scheduled me for thirty-three treatments and would allow me to choose hours as appointment times became available. At first I took whatever was open, but was able to settle into a mid-morning standard appointment. There were people continuing to work who needed the early and late hours, so I chose mid-morning. That worked very well for me since I finished with my treatment in time to go by the library or meet someone for an early lunch. I was determined to give myself

something pleasurable to do after each treatment so my feeling when leaving home would be of going out for a cheerful fun day. I would just "run by" and get my treatment on the way. It made for a nice mindset.

I read as much as I could find about radiation therapy, including all the pamphlets from the cancer center. It corrected many of my misconceptions. Instead of lying there for hours, most of the time was spent with the technicians placing my body so the marks were in the radiation field and checking all of the measurements. Once this was done, the actual time of treatment was less than a minute. Then they repeated the process from another angle. Ten to fifteen minutes after I walked into the room, I was on my way out.

In the waiting room, in addition to the TV and magazines, there was a large table with a jigsaw puzzle. When one puzzle was completed, a new one replaced it. I made several friends while working on the jigsaw puzzles. We would find ourselves chatting as we searched for pieces, awaiting our call. Sometimes I just moved pieces around and sorted colors. It didn't matter. It was enough that it occupied our time and minds while we waited.

We talked about our cancers, treatments, homes, families, and of things that worried us. It was difficult to discuss some things with friends who had not had cancer. With those who were there, it was not necessary to explain everything in detail and it was like talking shorthand. It still seems odd that we didn't cry when talking with each other. I suppose that's the difference between empathy and sympathy.

For the first few weeks, I felt only the mildest discomfort and, with a sense of satisfaction, I would put a big black X on my kitchen calendar for each day I completed another round of radiation. Then I discovered why they had said, "No ice on your breast during radiation," an idea that had made me shiver and wonder who would ever do that. The heat did not seem to be on the outside going in, but a glowing coal inside that felt as though it was radiating outward. It continued to get hotter and stayed that way until the end of my treatments, and even for a couple of weeks after.

When I proudly looked at my calendar and saw twenty-four "X" marks, I went in to shower and get ready for day twenty-five. My treatment was for the upper outside quadrant of my right breast, and went under the arm and up into the armpit.

That day, I lifted my arm in the shower and the skin slid away from my side in a sheet, leaving it red, raw, and oozing. I had to go on to the hospital and let them look at it, but received no treatment that day.

They said, "Take a week off and let it rest. Then we'll pick up where we left off." That was such a blow. I was so discouraged when I went home and could not mark off another day with my big black X. I could not continue with my countdown to the finish line until my body caught up.

I had an additional reason for wanting to finish on time. I had only been on one other cruise in my life and loved it. Some friends wanted to go to Alaska and it was my dream trip. Above all other wishes, that was something I never thought I could do, but we all saved and planned for over a year. I read stories and marked

maps and dreamed some more. Breast cancer had slowed me down, but my trip was paid for and everyone was ready to leave about two weeks after I finished radiation. I knew I would not be in the best shape but another delay in finishing the radiation would mean my trip would have to be cancelled.

With this delay, I had one week to spare. When I went back with nine days still to go, I told my technicians if they could not finish on schedule someone else would have to do it for me because I was going to Alaska, regardless of being slashed and burned.

I was exhausted from the treatment, but knew I could rest and eat and sleep while my friends watched over me in Alaska.

Chapter Four
Alaska After Radiation, May 1994

I was so determined that breast cancer, surgery, and radiation would not stop me from living the life I planned that the Alaska trip became a symbol of what I needed to do in the steps back to my real life.

My traveling companions were Marona Posey, a long time friend, and some wonderful members of her family. Marona, her sister, and I shared accommodations on the tour, and in an outside stateroom on shipboard. They were both born to be caregivers, lucky for me.

I have never been more tired on a consistent basis. Getting there by air was the hardest part as we flew to Seattle, where we had complications because of oversold space, and finally flew on to Anchorage, then Fairbanks. I was so excited by the landscape on the last leg that I was taking videos through the window of the airplane almost all the way. When you go to Alaska, there are not many times that you lack a beautiful view, but seeing it from the air was outstanding.

We arrived late but it was daylight up there, and they still had to load us on a bus to deliver us to the hotel. As the others prepared to go back out, see a little bit of the city of Fairbanks, and find food, I stretched out on the couch.

Marona asked, "What kind of food should we bring back?"

I mumbled, "Anything," and was out like a light. I don’t even remember the door closing.

When they returned with a hamburger, I was still resting but was watching TV because Jackie Kennedy had just died of cancer that night and they were showing a retrospective of her life. I was strongly affected by this news, having just finished cancer treatments. It had left me so sensitive to others who had cancer that my emotions were not as stable as they had been. I would find tears rolling down my cheeks at almost anything. I thought about being born the month after Jackie, and how lucky I was that my cancer was found in time and had been receptive to treatment.

The next day, we started early and spent a morning on a marvelous riverboat, the kind with the big paddle wheel. I was thankful there were chairs so I could sit on the top deck and see everything while listening to the announcements and the fascinating stories of what we were seeing. Just climbing the stairs to get to the top deck was about all I could do, but I managed to get some videos. We saw how the homes were built along the river, the place where Susan Butcher trained her dogs for the Iditarod, and where she lived. We saw a bush pilot make a short field take-off and return to land. There was an Alaskan Indian village where we got off the boat to wander, and the people showed us how their ancestors lived.

It was truly a great experience, and when we got back to the bus, we had an entertaining driver who told us about ways of living in Alaska that we had never heard of. I did get from the boat to the bus and back without crawling, but barely.

After lunch and a short rest, we were on our way again, this time for a visit to a gold mine. We were able to see how the miners sluiced to clean up the mixed rock and dirt and try to find any gold in the residue. We also had the fun of learning to pan for gold and most of us found little bits of it that we were able to bring home with us. All of this was unlike anything I had ever done before and I loved it. By the end of the day, I couldn't even remember where or what we ate. I may have appeared to be there, but I lived for the moment and everything else had shut down.

I do remember stopping to see the pipeline and taking a video, while a woman, one I didn't know, took it upon herself to give me a lesson in videotaping. She explained to me in a loud voice that I was supposed to be talking while recording so everyone would know where I was. I was very hoarse, barely speaking at this time because the cold winds on the boat and the small amount of talking I had done had strained my voice. I don't remember what I croaked, but she left.

Don't ever think you can overcome the after effects of radiation with strong will. No matter how determined the will, sometimes the body just says, "No, you can't." Picking up one foot and putting it in front of the other becomes a chore and I found myself setting goals for how far I could go. Some places got a longer look from me because I could stand still, resting while I watched.

Over those next few days, it became a little easier because we spent time on buses and a wonderful glass-domed train that let me rest as we traveled through this magnificent country. We were on the land tour for four

nights before arriving in the port and boarding the ship for the cruise part of our journey.

With the months of being totally involved with breast cancer, I had given little thought to the voice exercises and care of my vocal cords. I had started to cough a lot and the more I coughed, the more hoarse I became.

On the ship, I got more rest than I had on the land tour but I did get off of the ship to see the other sights. I fell in love with the little towns along the inside passage. An added advantage of cruising was the ship was right there and I could always get back and have the stateroom accessible. By that time, I had fallen into a routine of resting and sleeping. I always got up from the dinner table and headed to the cabin to get ready for bed. I was in survivor mode, protecting the little strength I had.

The trip home was more of the same, like I had been living in a dream world. I went straight to my own doctor. It was time for several rounds of antibiotics to get rid of the congestion and to get back to voice rest and exercises to protect my vocal cords.

Chapter Five
Swimming in Troubling Waters, 1994

Arriving home, I found other problems I did not expect. I had COBRA health insurance, the extension of the policy I had while employed. I had planned well for all of my health checkups and blood tests to be done before it expired in the spring of 1993, including a regular mammogram in January 1993. All was clear, with no problems anywhere.

I had researched and signed up for a catastrophic policy to take effect when the insurance expired. The new interim insurance had a $5,000 deductible and they had sent someone out to check me over. I was approved. Up until then, I'd never had that much medical expense in one year, so I figured I was paying them just in case there was a surprise illness. In fact, I only needed coverage until Medicare would take over about fourteen months later.

For the sum I spent in 1993, I was well under that $5,000 limit, so I never filed any claims. Most of what I paid the rest of that year was for those voice lessons to teach me how not to damage my vocal cords.

Then the mammogram in January 1994 found the tiny breast tumor. When I returned home from Alaska, I found my interim health insurance policy refused payment on the breast cancer treatment, claiming it was pre-existing. The total bills came to over $35,000, which I refused to pay.

I sent letters. I sat on the floor and sorted papers, invoices, tests, and copies of everything that would prove I had a clean bill of health when I signed up. I called my friend, Marona Posey, who was an attorney, and she suggested that when I write to them again I mention what "my attorney" had said. This was to let them know I was not going without legal advice. She also recommended when I wrote to them that I copy my attorney so the insurance company would see the reference. I had the facts, but I didn't have the power.

A collection agency started calling me with requests that escalated into threats that they would ruin my credit. It was so regular as to become harassment.

For a basically cheerful and optimistic person, I became a person being attacked from all directions, still half-sick from the respiratory illness, continuing to recover from radiation, and coughing all the time. I was frightened that I had something worse than nodules on my vocal cords and knew I had to have insurance. Medicare was just around the corner but I didn't trust they would take me after diagnosis if I were already scheduled for a biopsy. It was obvious that if the new interim health insurance would fight the breast cancer cost, what would happen with the throat cancer? I knew the answer to that. There were telephone calls, letters, arguments, and many sleepless nights.

The company finally paid the bills for the breast cancer, just over $30,000 for their share. With my $5,000 deductible plus the cost of buying the insurance for the year and a few small things they didn't cover, my share was about $8,000 total cost for the year. If I had not kept the paperwork, reports, and test results, I might have lost

my argument. I wish I had done a better job of filing and organizing because my papers were scattered everywhere and I didn't have copies of everything. (I now toss every bit of paperwork into one large laundry basket so I know where to look if I need any medical papers. It may be messy, but at least it's all in one place.)

It doesn't cost an insurance company very much to simply refuse anyone by claiming it was pre-existing and wait for the person to quit arguing. While it takes them a large folder on a desk full of others, their refusal takes over our lives.

My birthday was near the end of August, but I was not sure if Medicare would start on the first day of August, on my actual birthday, or on the first of September, so I signed up for Medigap to cover what Medicare didn't. Then, in September, I made an appointment with the ENT who had found the problem with my vocal cords the year before.

He was not pleased to see me and seemed to think I had not taken care of myself, ruining all the benefits that good therapy had accomplished. He quickly realized what had been going on in my life. A couple of visits was all it took for him to say I needed a biopsy.

I was just as sure that I had vocal cord cancer as I had been sure I did not have breast cancer. I could only hope I was wrong again but this time I could feel it hanging over me like impending doom.

After the biopsy was over, I felt so sorry for my doctor as he tried to tell me I had cancer. He had not believed it either, and it was hard for him to say. I could have said it for him because this year it was no longer the Big C that nobody mentions. He said it was

squamous cell carcinoma. Call it what you want, though, damn it! I had cancer, again.

It was November and I was scheduled to go to Gulf Shores, Alabama, and visit the beautiful beaches. This was something I had always planned to do if I could manage it financially, and I had shared a month's rental on a small condo right on the beach at November's cheap rates.

Against all advice, I scheduled my radiation treatments for December, refusing to start immediately. I left for the beach where I spent my two weeks of the month all alone, walking the pure white sand and getting used to the idea that I had to start radiation all over again, not knowing if it would kill the cancer or not. If it didn't work, it would mean surgery, the loss of my voice, and a huge change in my life. I cried all my tears out in the saltwater breezes, but I was at peace with it by the time I came home.

I was ready to start all over again, ending 1994 with radiation to try to stop this new cancer just as I had started the year with the first diagnosis. 1994 was not a good year, but there was more coming.

Chapter Six
Radiation The Second Time, Dec 1994

Starting radiation was easier this time. I knew the folks at the cancer center and I liked them. I got lots of hugs and some teary eyes from the professionals who would be working with me again. I would be with them for another thirty-three treatments, plus the testing, planning, and marking visits.

A new, quieter me met new people, worked new jigsaw puzzles, and made new friends once again. People turned to me to ask questions. In the space of a year, I had become an old timer. It wasn't what I had planned and strived for, but I seemed to be where I was meant to be. I knew the routine and the people. I could help.

The lower right corner in this new square of radiation marks came to the upper left corner of where I had been marked for the breast cancer treatments. My skin was tougher on my neck than it had been under the arm and down my side, and the pain was different since it involved a passageway that I needed to use several times daily. This time, the hot rock was in my throat and it became difficult to swallow and talk. They gave me a prescription called Magic Mouthwash that helped but never quite got to the right place to numb it. Toward the end of the radiation, I remember sitting at my dining room table, putting food in my mouth, and getting up my courage to swallow. I would prepare myself: get set, ready, go, as I flinched from what I knew was coming,

food scraping my raw throat as I swallowed to force it down.

When the radiation was over, I knew I was still in trouble. I could tell when the radiation oncologist looked down my throat that he didn't like what he saw. I didn't close my eyes. I watched his. As they released me from the daily treatments, I had instructions to wait to heal before going back to my ENT, but I went earlier. When he walked into the room, he asked what I was doing there since it was too early for him to be able to see clearly into my presently charred throat.

I told him, "It's still there. I can feel it all the time."

He looked down the throat, nodded, and then left. When he came back in, he said, "I'm sending you to the best in the Southeast, Dr. Glenn Peters, who's head of otolaryngology surgery at UAB's Kirklin Clinic. We'll have an appointment for you at the desk before you leave today." We talked longer. He was a very kind man, and he suffered for me.

To this day, Dr. Glenn Peters denies what I remember him saying. The way I remember it, he came in, held his hand out as he introduced himself, and said, "I hear you have a cancer you can't get rid of."

I thought, "At last, someone who says it right out front. I'm going to like this guy."

After his examination, he said, "We have to do another biopsy. There's a possibility that you could need a partial laryngectomy. You may need a total, but I have to get in there and see it myself in order to plan the right thing to do."

The biopsy was set for mid-March and my son brought me to UAB hospital for the same-day surgery.

As I awoke, he was sitting in the room with me, using his computer, when a nurse came in to check me out. When Dr. Peters came in, he explained to us that I would need to have a total laryngectomy. With these words, although I expected them, my last chance was gone.

He said the entire glottis was very small, more like the size of a child's, and removing the tumor would leave me with almost no vocal cords. The surgery just wouldn't work with a partial. He asked when we wanted to do it, on Monday or Friday.

I looked at Scott, who said that Friday would be better for him so he could be available for the weekend to be with me. It also suited me because it gave me a week to make some preparations for coming home without a voice and to shop for anything I might need. I could do my own errands this week. I was not disabled and sick; I just had cancer.

At home, I got started preparing. I called 911 and told them I would be here at this number but living without a voice, so they would know that if I called and didn't speak I automatically needed help. I also informed others who needed to know.

My friend Carolyn Chenault arranged to come down from Decatur on whichever day I would be coming home from the hospital. Scott would bring me home and would be my main contact. I gave different friends pre-made lists of who to call. I told my friends, "Do not come to see me in the hospital. There will be a messy, miserable few days right after surgery. Please wait 'til I am over that part or, better yet, until I get home."

We had a family meeting set up with the speech language pathologist (SLP), who was the person I would

need to help me with a new voice and other new changes. I needed to learn how I would live with a laryngectomy. It's easier now with groups such as WebWhispers.org and other organizations devoted to educating and answering daily questions about items you never thought to ask in the clinic, but I didn't have that support then.

My experience was better than most because I was fortunate to have as an acquaintance a long-time laryngectomee. I had met her twice about fifteen years before when I went with friends to her office. There was no particular reason for her to remember me, but I remembered her well. She spoke with an EL device that I later learned was a Cooper Rand, and at that time I had to pay close attention so that I understood everything she said.

Her words were special, and not just because she worked harder than most people to speak them. They were expensive words since she was a card reader, and I had gone with friends to have her read my cards. She would ask you to concentrate while she dealt the cards into a pattern, then would pick up the speaking device, put the tip of the tubing in the corner of her mouth, and start to explain what she saw. It was impressive.

A few years after that, I went back once again. This time, her voice was different and had a hoarse but more normal sound. Again, I had my cards read. I don't remember how accurate the readings were but both times she predicted re-marriage and both times I denied that would happen. The cards also didn't tell her there was a future friendship and connection for us.

Since I now knew that the next Friday would be my surgery date, I called Dorcus and explained that I was a former client but asked for a meeting about a different subject and told her the plans. She immediately changed her tone from crisp and businesslike to concerned and caring. She pulled out her appointment book and set me up for the first spot she had open so she could help me understand what was going to happen.

What a lovely lady. She took the time to talk with me and demonstrated how her TEP worked, even showing me how she cleaned and replaced it and how she coughed to clear the stoma. She also demonstrated an electrolarynx (EL). This enabled me to understand much of what my new SLP was telling us regarding voices. I understood I would be receiving a Servox, a very dependable brand of EL, and we would talk later about a date for having the tracheoesophageal puncture (TEP).

Dorcus talked a lot and was easily understood with the TEP as she covered some of the frustrations of learning to speak a different way. I remembered the voice part of the discussion far more than anything else I may have been told. There may have been talk of becoming a neck breather and the problems related to that with taste and smell, but I don't remember being as concerned about that as I was with how I was going to talk. This is true with most laryngectomees-to-be. This meeting took away some of the apprehensive feelings I had about the future.

Chapter Seven
Ma Bell and the Laryngectomee

The week before I had my laryngectomy, I made several calls to find out what was out there in the world of communication to help me. The telephone company had a special section listed in the front of the directory under Information for Customers with Disabilities. It seems that the same unit that is used for the deaf can be used for the speech-disabled, a text telephone (TTY) which has a keyboard. In my state, Alabama Relay Service provides a free service to relay by voice the message that you have typed in. They connect to your designated number and stay on the line. You can "talk" back and forth with their help. The states vary in the amount of financial help given. In Alabama, while the service is free, the unit itself is not. If I had not been able to speak at all and the existing methods were not available, I would have that.

Learning to talk on the regular telephone is just as frustrating as you might imagine. First, the physical reality of holding the telephone with one hand and your electrolarynx with the other is difficult enough, but add to that the attempt to write down a number or a message. Even the most thoughtful people don't realize or they forget the difficulty you are having, so it is your responsibility to explain over and over again or find another solution.

I bought a headset and hooked it up to the telephone where I would spend most of my time. In my

case, it was at my computer. I got a small plastic hook, the kind with the glue backing, put it on the side of the monitor, and hung the headset on that. It's handy, but out of the way and not likely to be knocked off. I made a point of answering from this set, or I asked if I might call back right away so I could move to the telephone where I had the use of the headset. I had a comfortable chair with a desktop on which to prop the elbow of the hand holding the Servox. Now I can write, drink coffee, or even play solitaire on the computer while I chatted. It was a great improvement!

High quality speaker phones help too, and the systems are much better than they used to be. Cell phones are now common and you can carry one around with you, but I still recommend a set of headphones and have used a wi-fi earphone quite well. Most of them are made with the idea of being small and unobtrusive, but I like best the mouthpiece that comes around to about my upper lip. If you get the speaker too near your stoma, you will get a breathy sound that sounds loud to the other person. If you use an EL under your neck, the buzzing sound is quieter when you have the mic moved up to just over your mouth.

In advance of my surgery, I called 911 to let them know that I would be home alone and, for a large part of the time, not able to speak. I asked for instructions about what I should do if I needed help for any reason. They were wonderful to me and told me they would put the information on my residence address that if there should be a "no voice" call, they should send someone out to check it right away. I tried to think of all possibilities. Even if you are using the electrolarynx, it could be left in

a room away from you. Notifying them of my problem seemed to be the way to go. This should be done even if someone else is usually there.

Your local fire department needs to know how to do CPR on a laryngectomee and there have been updated methods and equipment to help in this situation. The best way seems to be the increasingly popular Hands-Only CPR.

In the WebWhispers.org library section called How We Live, there is a category called Safety. There are links there to videos showing you the recommended method from the American Heart Association and Mayo Clinic. The University of Arizona has a wonderful video that shows exactly how to do this kind of CPR and explains why you do it that way. You can also find instructions all over the web. Most TV channels and leading newspapers and magazines have had articles published. AARP has a section. The idea is that anyone can do chest compressions on us, or we can even do CPR compressions on others. It is the safest and quickest way to help. But always call 911 first, and then begin CPR.

The most recent additions in text-to-speech apps, such as those on iPhone and iPad, get better and better. For us, they can be a lifesaver.

Chapter Eight
Laryngectomy - March 31, 1995

It was the wee hours on Friday and I couldn't stay in bed another minute. This was a life-changing day and having accepted the fact of the surgery, I just needed to get there, get checked in and prepped, and have them get me drowsy so I could surrender control and drift. My friend picked me up and dropped me off at the hospital, and Scott and Ruthie would meet me there a little later. The hospital had a large area where they would do the prep, and I stayed in there on a gurney after getting changed into a gown.

I don't know when they gave me something to make me sleepy, but I think it must have been early on because I don't remember much of that. Within the space of only fourteen months, I had the two breast surgeries and two throat biopsies, so it’s easy now to get those times mixed up, especially after a dose of whatever they used to make it all seem like a dream.

I do remember them rolling me out into the corridor and down and around hallways until they parked me at the foot of another occupied gurney, with another one at my feet. I was really groggy but I remember another row by my side and it seemed like a field of horizontal bodies, waiting for the bell to ring before beginning a ballet on wheels. The feeling was like being one of a row of cattle waiting for whatever was coming and you knew everyone stretched out there was hoping they got the right stretcher to the right operating room.

Then when they finally came for me, they moved so fast that it was almost as if the ceiling were moving in the opposite direction.

I remember the room with lights and seeing my doctor, and that was about it until I awoke in my room.

I would never speak again. At least, not in the normal way.

I felt totally relaxed when I woke up and was breathing easily, and for only a moment the idea drifted through my mind that maybe they hadn't done the surgery. I tried to open my eyes and, as consciousness returned, my automatic response to the figures moving around my bed was to try to speak to them.

My lips moved, but nothing came out. Not even a moan.

I had known I wasn't going to be able to speak or clear my throat, but it seemed so odd to feel like groaning and there was no sound, no vibration.

As the fog lifted, I remembered waiting for surgery, lying on a stretcher in the hall with the other people, waiting quietly for the show to begin. Now it was all over, and my voice was gone.

But I could breathe! I had expected to feel really weird, smothered, and distressed, but surprisingly it felt normal. I seemed to be breathing through my nose, even though I knew that was impossible. My trachea was no longer connected to that part of my throat, but was shortened and turned to a new opening at the base of my neck, a tracheostoma, more commonly called a stoma.

This would be my new lifeline. I would inhale directly into my trachea not far above the opening into my lungs. I practiced. One breath in, not too deep. One

breath out, trying to hold back a feeling of panic in case it didn't work right. Even though there were stitches and swelling, I was breathing easily. I had read that breathing was actually less difficult without the air having to pass through all of the restricting passages of the nose and down to the larynx, but I hadn't quite believed it.

There was a stack of paper with pens on my bedside table and a magic slate, the toy that uses a wooden stick to write and has a page you pull up to erase. I would find out that it was almost more trouble than it was worth to try to write a note because there were tubes all over the place. A tube went down my nose for feeding, a drain came out from the surgery site, an oxygen/humidifier mask laid loosely across my stoma, and suction tubes hung by my side when I needed to clear mucus from my stoma. The IV keeping my left hand literally tied up was one of the most annoying things when trying to reach for writing tools. But the difficulty in writing was nothing compared to the trouble of trying to get up and untangled enough to go to the bathroom!

My days in the hospital were busy with routine procedures and trying to get through each day so the healing would be that much further along. Every time I was awakened for vital sign checks, I had to wake up enough to let the aide know that she couldn't use my right arm. Signs on the door, the chart, and the wall at my head went unread most days, even though they said that they were not to use my right arm for blood pressure checks, so somebody had to remind each new person. Otherwise, I would awaken in the darkened room with the cuff going on the wrong arm.

Under normal conditions, a quietly spoken word would have been all that was needed. This was one of my first lessons in something becoming very complicated when it should have been simple. But I was mute, had tubes all over the bed interfering with my hands, and the room was dark.

We poured my liquid food and medication down the tube and I learned that a little water goes in first so the other doesn't stick. It didn't take long for me to learn to do this myself. I wrote a note and asked the nurse how and why. Her explanation made sense to me and then, on about the third day, a new nurse came and did it a new way. That was when I decided I'd better do my own feeding and medication because half my medication stayed in the dry tube.

Irrigation was not a new word, but I never knew its true meaning. They used a three milliliter syringe to squirt saline solution through my stoma and into my trachea, causing spasms of coughing. When I left the hospital, they gave me some little pink bullets to use, and many people still use those daily. This little chore was done about four times a day, and it hurt so much to cough that it was all I could do to act like it was all right. The purpose was to thin the blood and mucus so it would cough out. Otherwise, it formed a plug that became hard and blocked my breath, so it was suffer now or suffer more later when we had to get that plug out.

My son, Scott, was there in the hospital every day, working with his laptop and telephone as best he could from a hospital room, but always there when I needed him. My loving daughter-in-law or one of my long time friends spent nights, sleeping on the foldout bed in the

room. All I had to do was rap on the table to get immediate attention. Other than these three, I had a visit from my new laryngectomee friend, Dorcus, who was a marvelous benchmark and image for me. She was also an encouragement for Scott. He was able to see a woman who looked wonderful, was smiling, and was healthy. Her hands-free TEP speech was so good that I thought if I could talk half so well, I would be in great shape. She was inspiring.

My longtime friends Nova and Rick also came. Rick had had throat cancer twice, and the second time had a partial laryngectomy. I had been to see him in the hospital and after he came home, so I knew some of the things I would go through and I knew they would understand exactly what was happening to me. A few other close friends came with my permission after I was able to be up enough to walk the halls. These were the only people I wanted to be there. Other than these few close friends, I had requested not to have visitors, especially since I certainly couldn't make conversation.

All of my close friends respected my wishes, but one well-meaning couple came by. I was horrified to have someone come in while I was going through all of these very personal problems. It may have been all right with them to see me like this, but it was not all right with me. I wanted to do my learning, coughing, cleaning, tube feeding, struggles to the bathroom, and all of the cumbersome problems that go with surgery without anyone there but the health professionals and the few people who were taking care of me.

When I had my breast cancer surgery, I had a multitude of visitors for the two days I was in the

hospital and it was fine. My scars and bandages were hidden. I could take my pill and doze off while my visitors chatted. I looked normal, sounded normal, and was able to request sleep time or trips to bathroom.

A laryngectomy is different. It's messy. It can't be covered and when you cough suddenly and sometimes violently, mucus can be flung across the room. You need to irrigate and to vacuum out your mouth and stoma. For some, the medicines cause nausea and for others, including me, diarrhea. This is definitely not a time for visitors who aren't prepared for that.

About a week or so after I left the hospital, they sent a questionnaire to ask my opinion of their facilities and this was my answer:

April 18, l995

University Hospital Questionnaire

I entered the hospital on March 31st as Dr. Peters' patient for a laryngectomy. I found the entire staff to be extremely courteous, respectful, warm of manner, and friendly. I really liked them all. If I had experienced any major problems, it's possible that I could tell you how skillful they are. Instead, let me tell you what happens with minor problems.

When I left the hospital, my instructions were to clean the incision once a day with peroxide. Not one person cleaned my incision in the hospital. I started the morning after surgery gently cleaning the area and perhaps each nurse thought the other had done it.

My surgical drain was emptied regularly, but only a few people knew how to squeeze it and roll it to get the suction going properly. One aide tried to pin it up level with the area where the drain came out. I wrote notes about six times to say the drain was clogged. I don't believe they had ever pulled a pump off of the tube and used the back end of a Q-tip to push a blood clot through.

The urine container was left to fill for prolonged periods of time and we often asked that it be emptied. By the third day, I was there mostly by myself and I had developed diarrhea. It is awkward, to say the least, to try to make it to the bathroom under those circumstances without having to move a half-full urine container. On about the fourth day, I asked the nurse to empty it, and only later, when the aide had been worried about my urine output, did I look at my chart and realize it was not marked.

That same day, I had asked for Tylenol instead of something stronger, but made the mistake of walking to the nurses' station at 7AM. My night nurse said she would tell the incoming nurse. Three requests and three and a quarter hours later, I got the Tylenol. I have a feeling that if I had asked for Lortab it would have seemed more urgent. I found out later that Tylenol was not on my chart because no one expected that request.

On Sunday morning, forty-eight hours after surgery, I decided to try my own irrigation and asked for a nurse to be present to watch me. That

was the last time anyone checked to see if I knew what I was doing. I was sent home with a suction machine and have to assume it was for emergencies. The only thing it was ever used for in the hospital was a little suction around the stoma and saliva suction to keep me from swallowing. If it was sent with me for an emergency, no one told me what to do. Maybe it was for daily care, but how do I know?

I was also feeding myself by then and if Nurse Gloria had not already told me the order in which to do it, I don't think anyone else would have. Actually, one nurse put Lortab down first without preceding it with water.

I was not able to have BP readings in my right arm, and most of your staff picked up on that right away. A few times, I had to stop a new one and point the way.

I could have used some help with the tube feeding in holding it up. Having had breast surgery last year, I had difficulty in raising my one arm high enough. When I could catch someone they were willing, but I finally devised a method of raising my tray to the highest position so I could rest my elbow.

I am not picking on the nurses, but they are the caretakers on which you are most immediately dependent, the ones you see the most and are closest to. If they are not doing or overseeing the little details, it leaves the patient wondering what would happen if there was a real problem. I have the feeling that all these nurses are very capable,

but as in any job, problems are prioritized and little things slide. Yet your hospital is being judged by those little things.

The nurse stations are placed so no one can see down the halls. As I approached the station one day, I saw a little nude fellow dragging a sheet behind him, trying to get down the hall. There were seven or eight people behind the station but no one could see him. I couldn't speak, so I grabbed a lady from housekeeping and gestured wildly. Of course, when they realized there was a problem, everyone ran to take care of it, but it seems to me that a view up and down the hall would aid in preventing occurrences of this nature.

In some ways, it should be nice to receive a letter that complains about small things. It means there were no big ones. Please see that the charge nurse receives a copy of my letter.

Pat Sanders

In later years, I heard of many problems and solutions for the hospital stays. Noisemakers like small dinner bells are handy to get attention, new machines, games, boards, and electronic tablets and notepads allow you to preprogram questions or voices. There are Text-to-Voice apps for these and free programs for your laptop, iPhone, or iPad. Be wise and plan for that so you can type out the questions for the doctor's rounds or write out a request for the nurse.

Most complaints are that when the newly speechless patients ring for the nurse, a voice come on

that says something like, "Yes, how can I help you?" or "Did you need something?" Almost everyone resents it, and it feels like being kicked when you're already down. So prepare for it. Paper and pencil requires a real person being there to read it, but if you have a gadget that will talk for you, you can program it in advance to say something like, "This is a recording. I cannot speak. Please send someone to help me with a problem." Turn up the volume and when the nurses' station answers, play it. Other than that, ring the hell out of the bell! Of course, if you have caregivers with you, they can answer unless they have gone to the cafeteria, the bathroom, or to answer a phone call, leaving you alone. You may need help when they are not in the room.

I don't want to sound like it's the fault of the nurses answering. They have many patients and most can answer and tell them immediately what is needed. Your problem may be something like an accident that needs cleaning up or your need for a painkiller, but there's always the chance that it's an actual emergency. The type of problem makes a difference in who is sent to care for you.

Chapter Nine
Homecoming - April 5, 1995

Five days after surgery, Dr. Peters decided that I was healing well enough to allow me to go home. Everything looked clear, there was no fever, and I was doing my own feeding, irrigation, and drain cleaning. They told me to walk all I could, so I roamed the hospital halls. I still had the feeding tube in my nose and the drain from the inside of my throat coming out of my chest, but the doctor decided to leave these in for a little longer. The drains release the excess fluid from the surgical area and reduce the puffiness or swelling. The need for the drains can last longer for some than for others. Yes, I was to go home with these tubes and come back in three days to let him check to see how I was doing.

As efficient as they were in getting me packed up, it still took or seemed to take a long time to get me out. We had to wait while they delivered a portable suction machine. The nurse kept bringing more and more items to use for my immediate care at home. There were gauze pads, several boxes of the canned liquid food that was my main sustenance, saline solution, and irrigation supplies. We had to wait for the cart and wheel chair, as always. I had been encouraged to walk the halls, but wasn't allowed to walk out to the car!

Scott picked me up and we headed for home. The stay in the hospital was like living on another planet, going by their rules for what seemed like more than five days. I could hardly wait to get home and see my cats,

but I wondered what they would think of all the tubes draped around me, swinging every time I moved. I realized this could be a problem. My cats even found a telephone cord a fun challenge.

Arriving at my house was like being in a different world. My home was to become a learning experience, a place I had lived alone with my cats and where I was accustomed to taking care of everything. Now, for a while, when my telephone rang, I wouldn't even be able to answer it. My world was askew but I didn't care if it was upside down. I was going home!

My long time friend, Carolyn Chenault, had been notified that morning that I would be coming home that day. She left her home in Decatur for my house to stay with me for the next week. She would answer my telephone and be my voice with the outside world, in addition to providing any nursing care I needed.

Scott told me that my new Gateway2000 computer had arrived at his house and when he came to check me out of the hospital, he had it in the car. My spare bedroom was already set up as an office with a table in there to be used as the computer desk. This was to be another new experience, since typing was not one of my skills and I was not familiar with computer language. I knew I would have to struggle to learn just enough basics to be able to fax a daily report to my son and to print out letters for mailing to my friends and family so they could stay up to date on my progress.

On the way home from the hospital, we stopped at a drive-through restaurant so Scott could get something quick for lunch. I felt a pang for the old days when he could stop by my house and I could whip up a couple of

sandwiches out of left over roast or even a four course dinner by the time he could get to the table.

When we arrived home, everything in the yard looked good. Trees had flowered and everything seemed to have grown a foot. As we entered the house, both cats were there to greet me and I was welcomed royally with lots of leg rubbing, tail waving, and meowing. Of course, they had to investigate every package that came in, sniffing the strange odors.

By this time, I had been up a little too long and after setting up my "feeding station" at the dining room table, I followed my hospital routine. I attached the cup to the tube in my nose, poured in a little water, then a little dose of medicine, followed by a can of the liquid food. It had to be done slowly so gravity could carry it on down. Scott was busy bringing in and unpacking the computer, and I left that to him while I headed for my own bed and a nap with a cat on either side of me. Those two critters were really glad their mama was home. By the time I awakened, the computer was making beeping noises and it was almost time for Carolyn to arrive.

The main thing I wanted to do on the computer was learn to write a letter and be able to fax it or print it. Microsoft Word 7 had so many bells and whistles that my heart sank. It was ludicrous to think that I, at age 65, was going to be able to understand what to do with all of the settings. However, Scott kept his instructions simple and I made notes. Step one, step two. Carolyn came in while we were working on this and joined us in playing with this new toy. Other than the necessary communication we were learning, there was a simple, old fashioned, solitaire game installed on the computer

and Scott taught us to play before he packed up and left for the day. Neither of us could leave the game alone, and I almost forgot I was an invalid and Carolyn almost forgot she was a caretaker!

I had to show Carolyn my medicines, supplies, and food, all the while writing notes about all my routine. She had brought a gift of a big brass bell for me to ring so she could hear me if I needed her. We decided that I would ring it a couple of times to call her, but if I rang it like crazy, she should drop everything and get to me. We managed very well with this part over the next several days and she was kept busy answering the telephone and reporting to everyone. We would sit at the dining room table and she would tell me who was on the telephone. I would sit and write notes to tell people this or that.

A number of friends stopped in to visit and my friend Kitty brought a large wedge pillow so I wouldn't have to sleep flat. Lying flat after ingesting liquids would just let them run right back up my esophagus, so I used that pillow every day and every night. Sometime later, when we realized this was going to be a permanent problem, we raised the head of my bed several inches off of the floor and tilted the entire bed.

Carolyn took her turn at pouring in my food. It took so long to do this chore and my arms would get so tired. I took care of my own feeding once I figured out how to prop my elbow up on a box so I could hold the tube, but Carolyn was right by me all the time in case something went wrong, which it did several times. We had a few cases of spilled liquids and my elbow slipped a few times as I tried to hold the cup and pour.

Sometimes it came out too fast or went down too fast, and finally the stitch that held the tube in my nose pulled out. Then we had to hold the tube in place, support the cup we attached to the end of the tube, and tilt the can we were pouring out of. The tube tried to come out and we finally taped it in place. You can be assured I didn't starve. We found ways to solve the problems!

Learning to shower the next morning was traumatic. I had taken one careful shower in the hospital, shocking all of the nurses because it was not on my chart. Now I had to start learning a way to bathe myself and still be safe. When I showered, I used a rubber shield over my stoma. It looked like a rubber nose, which had holes where the nostrils would be, with a strap to go around the neck. It worked pretty well. I didn't stand with a hard shower beating down on me, but did try to get wet without getting water into my stoma. However, no matter how careful I was, I still had several bad coughing spells. I already had a hand held shower massage so I could direct the water better, but it was nerve wracking trying to be sure I didn't forget myself and turn so the water would leak in around the neck piece or I would get a deflected spray up the "nostrils" of the shield.

Carolyn stayed in the bedroom so she could hear if I started to strangle instead of cough. She told me later she stood at the bathroom door listening, hardly daring to breathe, so afraid something would go wrong. The first time I washed my hair in the shower, I was terrified but determined that I was going to live my life as near to the way I always had as I possibly could. I kept the water

pressure light and used the spray in the handheld mode. There were a few times when the water would trickle down and around my neck and some would go into my stoma.

At these times, it was not just a matter of coughing a little. It hurt. I would try to brace myself against the shower wall so that I could get a deep enough breath to cough it out. A little water in the shower causing a cough shouldn't be worse than the irrigation I had to do regularly, but when irrigating with a syringe there was some control over when to breathe in and when to squirt the water. This way, the water chose its own route and time.

These days were exhausting. There was so much to learn and each time I tried something new, I wasn't sure how to handle it. One of the worst of these was the cleaning of my stoma, which was raw and sore. The stitches would catch on whatever I used to clean it with and I learned to be careful of tissues. Being light and flimsy, they would leave little bits of tissue stuck on the stitches. If I had a sudden intake of breath, those pieces would get in my stoma and cause yet another spasm of coughing. A big soft roll of paper towels soon had a home at my bathroom mirror. Dampening one of those gave me the softness I needed for my very tender stoma area, but the strength to not break off and pull bits of paper into my stoma.

The absolute worst of my daily routine was irrigating four times a day. I dreaded the irrigation because the purpose of it was to make me cough, and it still hurt terribly to cough. It always took a little courage to fill that syringe and get ready to squirt water into my

air passage, which would react by making me go into spasms of coughing. I didn't dare do this anytime after eating because I would cough until I gagged. Coughing would wake me during the night. Sometimes, it seemed my new life was one long coughing spell. At least the blood in the mucus was showing less and less, which was good news.

I was taking very little medication compared to what I was allowed to take, but I found a little Lortab liquid just before bedtime would guarantee that I wouldn't worry too much about anything at night. Still feeling the after effects of the anesthesia, the trauma of the surgery, and the loss of sleep due to coughing spells, I was napping off and on throughout the day.

Later there were my first attempts to talk with the electrolarynx. Under normal circumstances, our vocal cords provide the vibration needed to create our voices. Since my vocal cords had been removed, I would have to depend on this little machine to furnish the vibration in such a way that I could form words with those vibrations. I could use this Servox against my neck so the vibrations sort of echoed inside my mouth or, at first, while my neck tissues were still swollen, there was an oral adapter that looked like a tube that I could put in my mouth to transfer the vibrations there.

The tube of the oral adapter would hit against my teeth. It didn't sound right from my cheek and got in the way of my tongue, so I couldn't pronounce words clearly. All I could hear was buzzing with something that might be a word every now and then. About the second day home, I pulled the oral adapter off and starting trying, very gently, to use it against my neck, which was

still swollen from the surgery. I would try to talk to Carolyn or my family and friends when they came by, and they couldn't understand me. I was embarrassed because I couldn't make it work and they would look intently at me and then shake their heads, obviously embarrassed that they couldn't understand me but not wanting to say it. I think we were all ready to say, "This isn't going to work!" I practiced with simple words and, while it seemed I wasn't progressing, I was getting used to where to put the Servox on my neck to give the most vibration and the least buzzing noise from the vibration.

It was surprising when I got a word out that did sound like what I thought it should and this did start to happen occasionally. I had been told it was going to take a lot of practice and that was certainly true! When I practiced, I had to ask Carolyn to turn her back to listen when I realized that because she is somewhat hard of hearing she had learned to read lips a little too well. It wasn't a good test of my enunciation!

Saturday, three long days later and eight days after surgery, we were to meet the doctor at the hospital. We almost didn't get to keep that appointment. He had told me to meet him there on the eighth floor where I had my hospital stay. I knew where I had gone in for surgery, and I knew they had moved me to a room on the surgical nursing floor after it was over. It never occurred to me that it was in a different hospital, and that it had been a block away. We went to the place where I had gone for surgery and wandered all over looking for anything familiar. Someone finally explained where we needed to go. I was a nervous wreck by the time we finally got there. We were standing at an intersection in the hall

wondering if this was the right direction when we stumbled onto Dr. Peters as he was finishing his rounds. All nervousness vanished. We had found the right place!

Dr. Peters had three other “white coats” with him and we all trotted down the hall to an examining room. I wrote, “When can the feeding tube come out?” and he reached over and started pulling it out. It was wonderful not to have that sticking out of my nose and to be rid of the tape that was attempting to hold it in place since the stitch that was holding it was gone. He also removed the drain, and that was rough. Dr. Peters kept saying, “I’m sorry, but it’s the only way to do it.”

He pulled some more until it broke loose. I had not realized how far up it was until I felt the pull in my throat. Then he took the stitches out around my stoma. He had to snip and pull them one at a time and there were a lot more of them than I thought. It was a rather painful time but I left there feeling about two tons lighter and with permission to drink my liquids instead of pouring them down.

I had to be on the liquid diet for a couple of days to be sure I was swallowing well and that there was no leakage. I drank milk shakes and warm broth and tea and juice, but no citrus. Even a little acid made me strangle and cough. It stung my throat. Almost anything could start that ugly cough. But I seemed to be well-healed enough to try some real food, so Monday morning I fixed very soft scrambled eggs with melted cheese and thinned down grits with butter. I took small bites and chewed, even when it didn't need chewing, then swallowed with care, but it was all I could do to keep from wolfing it down. I don’t know when anything ever

tasted so good. Except maybe the instant mashed potatoes with sour cream and butter that I had for supper.

On Wednesday, it was time for my friend Carolyn to head for home and almost time for me to be on my own. She had laughingly said to several people that the only thing I needed her for by then was her voice. I'll be forever grateful to this friend who put her own life on hold for me not just once, but several times. Another friend, Marona, came to spend that night and was taking me to the doctor the next day for another after surgery checkup.

Chapter Ten
Caregiver's Tale, April 1995

Even though I have since talked with a lot of families over the years, I did not understand the frightened feelings of the ones that care for us until I asked my friend Carolyn to write an article telling how she actually felt watching me struggle to learn this new process the week after surgery.

Home from the Hospital
by Carolyn Chenault

On my way to Birmingham to spend the first week home from the hospital with my friend Pat Sanders, I worried. What if I poured the liquid "food" too quickly and strangled her? How could I help her if she got strangled? Before going to be with Pat, I had talked with my daughter, a nurse, who had warned me to be very slow in pouring. My mind was racing with "what if" thoughts and how I could best react if one of my "what if" worries actually happened. I was bringing her the gift of a brass bell to ring when she needed me, but suppose I slept through it?

To start with, just looking at her feeding tube hurt me, not Pat. I wanted to remove it, because it was foreign and unnatural. It had to hurt! When

Pat, at home, had her first meal in the tube going through her nose, I almost froze with horror. I had not seen her being fed this way in the hospital. To my amazement it flowed down easily, she did not get strangled. We needed no help! Except she did get hungry and what in the world could we push down that tiny tube? When you become a mother you acquire an instinct to feed and even though my children are all grown, that urge remains strong within my being. I even entertained such wild thoughts as: could we put a steak, potato and salad in the blender, puree it, and pour it down? Before I had mastered my plan, several days had passed and it was time to go in for a follow up with Dr. Peters. He removed the tube! One of the happiest moments for both of us was that day. Then one more day on liquids to be sure there was no leakage, and much to my relief she was able to eat a very soft scrambled egg and "watery" grits. Her bite or two turned into several. The woman was starving to death! A friend had made some wonderful potato soup. Next time, Pat tried a few spoons full of the liquid contents of the soup then added bits of the soft potatoes along with the liquid contents. She was feeling better. My, what food does for one! And I was happy, too!

During Pat's first night home from the hospital I was anxious about going to sleep. My "what if" syndrome set in again. What if she needs me and I don't hear her? What if she chokes and can't call

out to me? The list of "what ifs" continued through the night, none of which occurred. She had the bell she could ring if she needed me and I listened for it all night long. Pat had rested well and she wrote to me the following morning that it was always nice to be home and in your own bed. I was worn out with "what ifs", but the next night I turned them loose and I rested too. Being a caregiver does not mean you do not care for yourself and your needs. If you don't take care of yourself, you can't function at 100% for the person who needs you.

I remember the first practice with her Servox. She had her booklet she had been given with lists of words to practice. To avoid tears I made myself giggle inside quietly like a little girl poking fun. "Pat's got a Dick and Jane book!" One turns to any thought, no matter how juvenile, that will make you stop tears. She practiced. I listened. And it got easier for both of us.

At one point, she realized I was reading her lips. I have a hearing loss in both ears and wear hearing aids in both, so I had gotten pretty good at lip reading. This didn't tell us how her words were sounding with the Servox so I had to turn my back and listen to her to find out if I could understand. Practice was successful; she got better.

When Pat would irrigate or clean her stoma, I felt the most pain. Although I could not see into her throat, the stoma was my window to seeing what had happened to my dear Pat. It reminded me, that hole at the base of her throat, that a part

of her had been taken away. That part of her would never return. I would hold the light and mirror so she could see better and use both hands free for the irrigation. She would gag and cough. I would fight back tears and pray for God to help her, for I could not. All I could do was be there to hold the light and gag with her in my heart. With each irrigation and each cleaning, it got easier to do. It became a part of her and not a strange occurrence that was happening. She gagged and coughed less, and though it continued to happen, it was more controlled, more natural. Or maybe it just wasn't as scary anymore. We were learning to live with what must be done.

Being a caregiver means you take on pain, knowing that someone you love is in pain and suffering. In Pat's case, it meant her entire life was being turned upside down. I did not want this to happen to my friend, but there was no way to avoid the changes and the new life we would have to carve out for our long lasting friendship. To quote Pat, "You do what you have to do!" And in doing, we outgrew the pain. We overcame the heartaches and went on with our lives to make new memories together. Pain of the caregiver is an okay thing. You just don't allow it to run rampant and get out of control. You do what you have to do and love being able to be there when someone you love is in pain. How lucky one is to be a caregiver. You have the opportunity to give that touch on the

shoulder, the hug, you cry together, and yes, even laugh. You heal together.

Chapter Eleven
In My Own Words - April to June, 1995

My first real letter was written on my new computer exactly two weeks after my surgery:

To my friends:

As you can see, I now have a computer set up and fax sending capabilities. I can now bore everybody regularly with reports of my progress.

I had my postoperative visit to Dr. Peters this morning and his residents beat him to the door. All tissue margins are clear of the cancer and they used that phrase you always wait to hear, "We got it all." Dr. Peters himself was very pleased with the way it went.

I don't have to go back for three weeks and then just to check to be sure everything is healing properly. I no longer need someone to stay with me and visitors are allowed. I may even borrow your voice while you are here to make a telephone call or two. Don't worry, I will use my friends who are appropriately nasty to call and straighten out billings.

I have a little machine to hold against my neck that enables me to talk and I do fairly well with it, but it doesn't sound like a regular voice and you will have some difficulty understanding me. By the time I learn to use it well and you learn to hear it well, I'll be going back in for same

day surgery for a tracheo-esophageal puncture and voice prosthesis. That should get me started learning to talk the way I will the rest of my life, or until they come up with something better.

My diet has progressed since Monday from soft scrambled eggs and watery grits to this morning when the eggs were done and the grits firm and to be really wild, I added toast for the first time. One of my friends brought potato soup and that has been wonderful. I fixed soft over-steamed vegetables for my supper last night with a side dish of macaroni and cheese. Each day is better but it is a long way to go to a steak dinner. When they rebuild your throat, it is necessary to learn to swallow again.

I will not be attempting to answer the telephone but all messages will be gratefully heard, and please include some of the latest gossip! I need to experiment with talking on the telephone; however, should we try and all is not going well, we'll just say goodbye and hang up. I can always fax someone and ask them to make the call for me to get a message to you.

Thanks to all of you for caring and praying and watching after me.

I love you all.

Pat

Over the next few weeks, I sent regular updates to friends and family members. They're only important for my purpose here because they offer a real look at what those early days were like, a glimpse into an adjustment

period that I'm now so far removed from. This is what that time following my surgery was like:

Dear Friends and Family,

Every day is getting better. My energy level is so much higher that I have to be careful not to try too much, too soon. I get out of breath and that makes me cough so I walk slowly to the mailbox. One of these days, I may adjust to being a little old lady, but I think that will be about 20 years from now.

Scott and Ruthie brought groceries yesterday and I was ready to attempt some real food. I cooked chicken and potatoes and it was wonderful. I don't even dream of the things I can't eat as I know they will come and when you add slowly, you appreciate each dish.

My next door neighbor gave me a darling haircut yesterday, and then I had some company to show off how good I looked without my scraggy hair.

My computer came the same day I came home from the hospital and Scott set it up. That would be twelve days ago. I have picked it up pretty fast and every time Scott comes over, I have a series of questions on what, why, and how. For those of you who know about computers (I don't consider myself among that group), I have a Gateway 2000 4DX2-66 with a HP Deskjet 540. Whatever that means? To me, it means I can write letters and play games, and yes, I have Solitaire.

I promise I will write some individual letters later, but it is too hard to tackle right now.

Scott and Ruthie both think I am much easier to understand but in person so they can read my lips as they hear. The telephone is still difficult and after I make one of my smart remarks that doesn't get thru, my favorite saying is "Never mind." Everybody understands that!

As for other problems, they are minor. I am having problems sleeping that I hope will resolve itself. I sleep at a 45 degree angle, and the position is not what I'm used to. Also, I tend to feel smothered occasionally. I am not in any pain. There is some discomfort and soreness in neck and throat.

My spirits are fine. I knew before I went in for this surgery that as long as the cancer was removed, it would be all right if I never spoke another word, and it's so much better than that.

My cats are keeping me company and are quite happy with a mama who goes back to bed to rest every now and then. One of them has her own pillow on the bed and follows me every time I go toward the bedroom.

Thanks for all the calls, cards, and letters. Love to all.

Pat

Dear Friends,

Looks like I have traded my old addiction—talking—for my new one, the computer. Scott

keeps coming over and adding things. I'll have to stay up all night just to keep up.

I am still sticking with fairly soft, bland foods, but can swallow almost normally now. I went out this morning for the first time alone. Can you imagine my car sitting in the garage for three weeks? Thought I'd better give it a trial run, since I am going for a massage tomorrow morning and that's a pretty good distance, but I'd drive to the other side of the moon for a massage.

I still have a great deal of difficulty with the telephone. Hardly anyone can understand me. In person, however, I do much better.

If you want to come by to see me, leave word when you would like to come and most likely it will be okay. If you have a fax, leave the number and I will get back to you. Otherwise, I'll get someone to call.

Note: I have incoming fax now in operation. 995-xxxx. Open 24 hours a day, and it will not disturb me if you get the urge to send something in the middle of the night. I'll just wake up to a surprise the next morning.

Physically, I'm gaining strength, and will slowly be getting back to normal.

For those of you who know her, Dorcus has been wonderful to me. She came to see me in the hospital and is coming to visit tomorrow afternoon. It's such a help to talk with someone who's been there.

Much love to all,

Pat

Dear Cousins,

I've been planning to send out another report on my condition but there hasn't been much change, and I certainly haven't been doing anything interesting. Got your sweet message and decided to sit down right now and reply.

I have my next visit to the doctor next week but I had a very raw throat and some difficulty swallowing this week, so I went in for him to have a look. He said it was probably a viral patch and would get better by itself. I did ask for permission to have chewable vitamins, cough drops, etc. and he said that was fine. When I was having radiation, they gave me lists of all the things I couldn't have. They should have given me lists of what I could have. It would have been shorter. The outside of my neck still has some really hard places and dissolving stitches that show so I guess the inside is that way, too.

I get so impatient. Once the surgery was over and I came home, I was ready to go slowly but steadily in everything as long as I was progressing. Then, when I had to take a step back, I didn't like it much.

Bob and Pam have been in touch. He called the first week I was home from surgery. Carolyn answered and thought he was calling for a report on my condition and he didn't know anything about it. They were talking at cross purposes and he wasn't understanding why I couldn't talk to him. Pam said he had been saying for several days

that he had to call me because something was wrong. I wrote them a quick note so they would understand and got the funniest letter back from her. She has a wonderful sense of humor. One thing this accomplished was her immediate health check up from one end to the other.

I've been saving copies of most of my letters and faxes to remind me later of different stages of recovery. I think I might write an article on this type of surgery. Four out of five people who have it done are middle-aged men who have been long time smokers and drinkers, and men don't usually detail what is happening to them. Maybe I can help some other people through it. We'll see about that later.

Love, Pat

On May 5, 1995, I'd been home for one month and sent this report to my friends:

Dear Everyone,

Let's get the health report over first. I had a little problem last week with my throat feeling raw and swollen so I went in a week early for the doctor to take a look. He said it looked like a virus and would go away by itself, and he would take another look at it when I came back for my regular appointment.

He could still see the thing he thought was a viral patch, and he says it probably was tonsil tissue, but he did a biopsy, which was no fun at all. He sprayed some anesthetic and reached in

with a tool that looked like a cross between pliers and pinchers and twisted out two pieces of flesh. I nearly came out of the chair. He'll call me Monday with results. Then, after that shocker, he seemed to think I was doing well enough to test to see if I would be a good candidate for this next surgery. The speech therapist, Nancy, told me immediately that this was going to hurt. So what's new? They think I will be able to learn to talk this other way. To determine if I could, they put a tube down my nose and covered my stoma with the other end and had me blow. At first, I was able to make a little noise, but by the time the doctor came in 10 or 15 minutes later, I was not able to make a sound, and I tried until I was dizzy. They decided that my throat was too swollen, and we needed to wait a while. The doctor said it should have been eight weeks before we tried this instead of five, but I had done so well with everything else that he pushed it a little. He said to come back in a month, so I have an appointment on June 8 to go through this again. They said it won't be difficult next time. Next, they'll sell me some swampland in Florida, really cheap. Ha!

If all this works out right, I should have the surgery just after the middle of June. Scott took me down to the doctor. I had driven myself last week and have been going to the grocery and library. I was doing so well but my car broke down Wednesday. I could not even call AAA. The hardest part is learning to rely on others to take me places and get me out of unexpected trouble. I figure I'll

have to have it done since I can't get another car for what that will cost, and I'm going to drive it as long as it will last.

I have permission to eat anything I want to try. Actually, they encouraged me to use my swallowing muscles as much as possible.

NOTE: It is now May 9th. I decided I wouldn't send out the above letter until I got the report back from the biopsy. The doctor called last night and said that it was lymphoid tissue as he had hoped and everything was fine. For those of you who think I've had such a wonderful attitude, hold some of that praise because there were spells this weekend when all I could remember were the other tests and biopsies and thought, "What if?" I'll be settling back down to normal now and can concentrate on getting my car fixed.

Again, I don't know what I would have done without Scott. He has done all the telephoning, questioning, ordering, moving, etc., and now the transmission on my car again. We gave up on the dealer and he had a transmission company pick it up. Hopefully, I'll have wheels in a few days.

I talked with Dorcus last night (the lady that has had the same surgery) and she asked me to come by as soon as I can and she will help me with using the Servox (voice machine). She used one for a long time before she had the last surgery and can give me some clues. I'll be using one for at least a month and I still have to do that testing to be sure I'll be a candidate for the other surgery.

The computer is still taking up a lot of my time. Scott signed me up for CompuServe so I have email. Now, I just have to learn how to use it.

Love, Pat

Throughout my recovery, I also put down on paper some of my private thoughts that I couldn't bring myself to send out to anyone. My friends and family all think I can do anything. They think I am smart and brave and can tackle anything, handle any results. Today it all came crashing down. I felt battered from every angle. Nothing was going right. I was trying to get through the day scared out of my wits and then the voice I was expecting to hear wasn't there. I don't like losing control of my life. I guess you could call this a private addendum to the letter describing the doctor visit:

After being frightened out of my wits by the impromptu biopsy, I was not ready for anything else. To approximate the feeling I had during the other test, imagine having your mouth taped shut with a small tube coming out that you can blow through but can't breathe in. They tell you to take a big breath though your nose and then they firmly pinch your nose together and say to blow through the tube. You blow as hard as you can and no air goes through the tube until some air starts to leak around the tape. They let go and you expel air from your lungs and breathe in rapidly several times, and they say, "Now let's try that again."

After a few times, the tears started to roll and the therapist was trying to tell me it was okay

and asking me if it was hurting. Finally, her assistant asked, “Are you scared?” and I nodded while the tears just kept flooding the office. We had to wait about fifteen minutes for the doctor to come and by the time he got there, it was even worse. The first couple of times I had gotten a growl sound, but by the time he came in my throat had swollen or, more likely, the tube had shifted to a more swollen part. I could get no air out and no sound. Nancy told me I wanted to do this so badly that I was trying too hard but in reality, all I wanted them to do was leave me alone.

When we left there, I never quit sopping up the tears...all the way to the car and all the way to Scott’s house and all the time I was waiting to go to Shari. She worked on my neck and shoulders for the whole hour and by the time she was finished, I was thinking I might be normal again. We got back to my house at about 6:30 and I was in bed by 9:00, just totally exhausted.

Today, I tried to write the report to my friends, and I was going to go back over it because it sounded so negative to me. It was after five o’clock before I realized it and I had lost a whole day. Tonight, I started with the tears again and I spent some time just thinking of why.

First, every doctor I’ve been to since all this started has said, “I don’t think this is anything,” or “I don’t believe this is cancer,” or “98% cure rate,” and each time they have come back to eat their words. So when Dr. Peters says he thinks it is nothing, but let’s be sure, it’s echoing all the

others and I'm scared to believe it. With the shock of this in my brain and the new raw place in my throat, I was not in the mood to play. What they did then was reminiscent of them trying to put the vent in my stoma in the hospital, and that was sheer terror. This felt like a complete lack of control over my own breathing. It was perfectly safe while a therapist was there, but try telling that to an overloaded brain.

I took a small dose of medicine tonight so that I will sleep comfortably, and with a good sleep under my belt, maybe I can have a better day tomorrow.

I'm going to try to do this more often, so I don't forget and think later that it wasn't so bad. This fear is more than bad.

Good Morning,

Let me bring you up to date. I had to go to the doctor yesterday… again. Marona took me. That was a problem, finding someone to take me. My car is still in the shop and Scott is in Nashville. My stoma was closing and making it difficult for me to get enough oxygen to do even normal things. I have such a small stoma anyway that it didn't take much. I was not feeling too good about this because of the episode in the hospital when they tried to put in a stoma vent; however, Nancy had stoma buttons which go into the trachea, but they don't curve down in. She used a deadening spray and put in a very small size to start, size four, and she gave me a size five to try next. She

thinks that if we can get to size six, that will be as big as I can go. She told me that if the four came out during coughing spells, go ahead and try the five. We were not even home when I had a big coughing spell and it popped right out. The spray was wearing off and I could feel it touching in my trachea and I couldn't quit coughing. When we got home, I worked out a way of putting a collar around the button to keep it from going in so far. I left it out completely and had supper, got ready for bed, and then tried it, and I could not get it to go in. Talk about frustrating. Nancy had the advantage of knowing what she was doing and having a patient who had a local anesthetic spray. I was getting ready to turn the lights out and decided I needed to try one more time. It was then about 9:30 and this time, I didn't have to work with it very long before I got the proper angle to sort of twist it in from the edge. The collar helped to keep it from touching and I was able to sit quietly, but I was afraid to lie down or to move around very much. Sitting still and reading, I didn't cough and after an hour or so decided maybe I could sleep with this thing. I did. I was restless, and about three o'clock I coughed it out, got up, cleaned it up, and reinstalled it, so I'm feeling much better about working with it. I do not have to wear it 24 hours a day, and I think nights will do. The four doesn't have a big enough hole to get activity-level oxygen, but I think I'll get used to the four before I attempt the larger five.

So that was my latest crisis. I have to go back Monday or Tuesday for her to check.

Barbara is coming by this afternoon, around 3:30 or so, to do some work in my yard. That is what she wished to do for me, and what a blessing that is, since the pollens, leaf molds, etc., would really drive me nuts now.

Love, Pat

Dear Scott,

Would you call Glenda and see if she could drop me off in Homewood tomorrow morning? Tell her I said I'd serve breakfast at 9:00. I'm not begrudging the time to do the car right, but I will be glad to have it back.

As for exercising, I walk the hill twice a day and walk inside the house quite a bit, and even go up and down the stairs. Even the #5 button only has ¼" inside diameter and I am looking forward to stretching this far enough to get to the #6. However, I took the #5 out the other day, and couldn't get it back in. I had to go to the #4 for a half hour and with that size it is so hard to breathe that I feel like a weight is sitting on my chest. But then I tried the #5 again and succeeded.

Dear Friends and Family,

It will be nine weeks tomorrow since my surgery, and in some ways it seems much longer. I have had some running back and forth to the doctor to check on problems, but there has been

nothing serious enough to change any of the original plans. My next appointment is June 8th, and we'll see from there when they will want to schedule the next and—I hope—last surgery. I just stay prepared to roll with the next punch.

I can eat almost anything except things that would be hard to swallow, like popcorn. I don't want a husk stuck in my throat. I have not tried hot sauces and think I can live without those for a while. It gets so boring figuring out what to cook when I am cooking just for me. It's about time to start going out to lunch occasionally. I think I'm ready for that, being over most of the unexpected coughing spells. I've found that a hot drink helps avoid those, and I drink watered down coffee and tea at home all the time.

I can hardly wait to get back to something even halfway close to my former energy level. I am going tomorrow to talk to a physical therapist about achieving that. I never thought I'd need this kind of help, but if I exert myself I get weak and winded. Maybe she can teach me how to regain strength and still be able to breathe.

For Mother's Day, the kids gave me computer card games, poker in all its forms with a choice of opponents and solitaire in fifty different games. After I get ready for bed, I'll come back in and sit here playing games the rest of the evening. I keep thinking, just one more game...

Love to all and thanks for writing,

Pat

Hi everybody,

I went to the doctor June 8th, and the surgery has been postponed until we get a couple of things stabilized. I have a new stoma vent to help me stretch the size, which makes a difference in the appliance they use for me in the future. It is also helping me to breathe easier so I can do more without getting out of breath. I have had a lot of acid reflux so they have put me on a medicine to stop that and will give me something milder after a couple of months. For a while, I could eat anything I wanted but now even cream of wheat creates acid. My next appointment is July 6. I feel a lot more relaxed since I was not ready for another surgery yet. I knew my throat was tender from the acid and the stoma was getting smaller. Dr. Peters blames the scarring in the stoma, which is closing it up, on having had radiation. He says we'll get there. I'll be using my little talking machine longer, but I'm getting pretty good with it, and with the swelling down, I get better sound. I've had to learn to talk slower, and break it into words and phrases.

I haven't been going out much and last week it was terribly hot, in the nineties and humid. I didn't dare look at the heat index. I went to the library and got a bunch of books. When I got back in the car, it was so hot it was difficult to breathe. I have enough problems with that already! I am doing a lot of reading right now as well as playing with the computer.

All of the different doctors and therapists have given me things to do, and it seems to take so much time fooling with ME. I'm used to a fast shower, throw some clothes on, and be gone. I don't like being so occupied with myself. I never thought I was boring, but taking care of me is!

Pat

Friday, July 21, 1995
Fax To: Dr. Glenn Peters
Dear Glenn,

Have another problem and need your advice and possibly your help. I had a mammogram yesterday and a check up visit with Dr. Dumas at Brookwood Cancer Center. Everything looked great, including your work, but he called me after I got home to say that there are calcifications in my left breast and I need a biopsy. I had a biopsy on that breast nine or ten years ago, and then last year they removed an infiltrating lobular carcinoma plus clean lymph nodes from the right side. I then went for 33 treatments of radiation.

I understand from my reading that anesthesia is actually easier with a stoma, but I have some concerns about irritation of the stoma during surgery that could cause me more problems with being able to get a TEP. Considering the small size of my stoma and trachea, is this a proper concern? Should I go back to where I had my breast cancer surgery or should I come to UAB where you can let them know how you want this anesthesia done? My primary

concern right now is with recovering properly from the laryngectomy, your area of expertise. My present state of mind is that, if this biopsy shows cancer, I can do without the breast (as a matter of fact, I can do without both of them), but what you do will affect my quality of life because it reflects my communication capabilities.

Please call me with your suggestions, as soon as possible, as I will wait to hear from you before making an appointment.

Thanks,

Pat

I sounded calm, but I was shaking as I wrote the letter and faxed it to Dr. Peters. I kept thinking, "Not again. Please, not again." I'd had five surgeries in fourteen months, two different primary cancers, and now —less than four months after the fifth surgery—the possibility of it happening again was almost more than I could bear. I kept telling myself it was going to be okay, but the shadow in the corner of my mind questioned, "Is it?"

When Dr. Peters called, he assured me that either hospital should be able to take care of the biopsy and the anesthesia. I informed him I would be more comfortable where he could take a look at my stoma if there should be any damage to my airway so he referred me to a well-known oncology surgeon at UAB who saw me shortly thereafter and set the date for the biopsy.

When I went for my pre-op tests, I was able to talk with the young doctor who would be doing the anesthesia. As I expressed my concerns, he assured me

over and over that there would be no damage to my stoma, they would just drop a small tube down in the trachea. I sat there picturing them pulling it out, dragging across the lip of my stoma that was stretched out enough to breathe properly for the first time in several months, when I realized he was placating me and soothing this little old lady who talked with a buzzer. I leaned over, put the Servox up to my neck, looked him in the eye, and said slowly and firmly, “If you mess up my stoma, Dr. Peters will have your ass!”

His jaw dropped as he looked at me, at his papers, and then back at me. He finally swallowed and said that if the surgeon didn’t have to cut deep, maybe they could just lay an oxygen mask across my stoma. Now that was the kind of reassurance I needed!

If you are having a procedure scheduled and you think something is wrong, speak up. This is why they mark sides L and R so surgeons don't cut into the wrong side! No matter how many people say later, "Mistakes were made," it doesn't help you if you were the patient. When I hear that phrase, "Mistakes were made," I know someone is trying to crawl out from under being blamed. If you are the least bit uneasy, tell them. At some point with surgeries, you have to accept the inevitable and just put yourself in their hands. I knew I had done all I could do. I never knew exactly how they handled the anesthesia, but to my great relief, my stoma wasn't damaged.

The report was to be back that Friday and by that afternoon, I had worn the wax off of the wooden floor near the telephone. When I hadn’t heard anything and lunch time was long past, I called the doctor’s office.

They took the message and said the doctor would call back.

While I waited, I started to get more and more scared that the reason the nurse had not given me the news was that it was bad and the doctor himself would have to speak with me. The longer I waited, the more convinced I was that I had cancer again. I had never faced that I might die. I never believed my cancers would kill me, but if this was another carcinoma or a metastasis of one of my other cancers, then what next? I was terrified that my immune system had failed and that if I had cancer again, it might not be the only one growing in my body.

It was almost time for the doctor's office to close and I called back, pleading for the nurse to get a result. I told her I could not wait until Monday. She said the doctor had gone to a meeting but she would see what she could do.

I couldn't let myself sink any deeper into depression so I sat, fists clinched, breathing slowly and deliberately, forcing myself to make mental lists of things that would have to be done. I never left my chair and I never knew how long I sat before she called. The report? I didn't have to worry. It was not cancer.

I thanked her and hung up, and then fell apart. Every muscle in my body started to lose tension and I cried my first tears of the day. My friend Carolyn, who had stayed with me the few days since the biopsy, was napping, which was her way of dealing with the tension, when she heard me. She came running down the hall thinking the worst. I was barely able to tell her that it was all right as I gradually accepted that I was going to

have a chance for the future I thought might have been taken away.

Chapter Twelve
Online and Local Groups, 1995

Even though I was a computer illiterate, I learned a few extra things every week. I signed up for CompuServe and used it a little, but was afraid to do much because almost anything I did could get me in trouble and I didn't know what buttons to push to get out of that trouble. I finally read some how-to articles and, with them carefully opened beside me, I went into the Compuserve practice forum. The screen looked just like the picture in the magazine.

After some practice sessions, I was ready for the big time. It was quite expensive to stay online back then so I knew I had to find what I wanted, download it, and then read it offline.

To pass the time, I had been trying to piece together my family tree. It was interesting work and did not require talking. I had so little information that my tree was more like a scraggly bush, and I had noticed a CS forum called Roots. I thought I could learn something there. Unknowingly, I had picked a huge forum and when I clicked to download all the messages in a topic so I could read them offline, my computer began flashing lights and buzzing and clicking for about twenty minutes. I was amazed to find I had in my files over 1000 letters, all on the subject of genealogy! I set out to learn what I could about finding my family from the past.

My next trip into this strange world was at the CS forum called Cancer, and going through the same procedure, I ended up with several hundred letters divided into different types of cancer problems, support groups, and even one called “The Coffee Shop,” in which you could talk about anything and everything.

I selected the heading of breast cancer since that was the first of my two cancers. I read into the evening, and I cried and laughed as I wiped away tears. I started to recognize names and people and saw them getting answers to their questions. I knew I had found a home with these people who could tell each other that they were sick, hurting, or afraid. I celebrated with those who had just finished treatment, and wept for those who were just discovering what had to be done. There were caregivers asking advice, oncologists answering questions with as much honesty as I have seen anywhere, patients writing to other patients to encourage them or to help them understand procedures they had learned from firsthand experiences.

I didn’t get to bed until the wee hours, and awoke early to write my first letter in the cancer forum. I became an active member and communicated on a daily basis with both new people coming in and the long standing members. I helped, and I received help. I could not think of a more fulfilling way to live.

Surprisingly, there was a lot of laughter on this forum. I think we had learned to enjoy every minute. I became determined to check in with these new friends as often as I could, whether it was for their needs or mine.

As I read the other categories, I eventually wrote to ask about laryngectomees and had a few people answer.

I counted seven of us and was able to ask a few questions and get answers from them.

I finally decided that it was time to attend a local support group meeting. I mentioned this decision in a message to a new friend in the Head, Neck, Lung section of the CompuServe Cancer Forum at the end of October, 1995:

> Just got a flyer in the mail of a Support Group Meeting at UAB for Head and Neck Cancer this Thursday. I will be there.
>
> I'm not one to need a lot of actual support emotionally, but I would like to find out if other people have noticed some of the same things I have. For instance, it's been seven months since my surgery and I've not had one spell of sinus trouble. Is this a plus that is likely to continue? My doctor is a great believer in irrigation. A laryngectomee friend said she used to have pneumonia-like infections often until she switched to this same doctor. Since she started irrigating, she doesn't have that problem any more. I am planning to use a humidifier in the bedroom this winter. I wonder if other people have found things that made their life easier. I don't mean special things like a shower shield. I've already quit using that. Just everyday hints that I might not have thought of or found in the books.
>
> Guess I'll get my chance to compare notes Thursday.

One of my steps along the way since surgery happened when a lady spoke to me as I waited for an elevator at the clinic. I was on my way to the support group meeting when she gestured toward my bandanna and asked if it wasn't awfully hot today to be wearing a scarf. I pulled my Servox out and said, "Sometimes you have to do things you might not want to do."

Then she asked if I wore that to cover my scar, and with a smile I answered, "No, I do this to keep the bugs out." The elevator arrived at that time and she got on the elevator with me, turned and said, "Well, I guess that would work." I had made my first joke about being a neckbreather.

When I think of all the things I could have learned in the months it took me to decide to try a meeting, it makes me very sad that I wasted that time. I was warmly welcomed by all, and knew immediately that I would be coming back every month. Later, Scotty Chandler wrote to describe coming to one of our support group meetings:

Our Support Group! What Is It Like?
By Scotty Chandler

If you arrive early, you see a few people milling around talking and most likely drinking coffee. They might be laughing at something or be in a serious conversation, but you can bet somebody will say hello and welcome you or wave with a, "Good to see you again." They come from different cities, not just the Birmingham area,

some from as far as 200 miles away. We have had guests from Chicago, Boston, and even my family members from Texas to "just see what y'all talk about." You might see a visitor from the American Cancer Society, a speech pathologist, a student, or a relative of a patient who is still in the hospital. You just never know who will be there. We all have one thing in common: we come to learn in order to help ourselves or someone close to us. Each has a distinctive story to tell.

Everyone signs in and leaves their address if they want to get on the list for the monthly newsletter, and stamps their ticket for free parking in the deck. When the meeting starts, we introduce ourselves and give a little background so that our new guests and visitors will know something about us.

Then we discuss things of general interest or problems someone is having. We may ask questions like: When will the swelling go down in my neck? How do you talk so well with the Servox while I can't get a decent sound? How long do your batteries last? I'm scheduled for TEP surgery, what can I expect? How do you take care of the prosthesis? What do you soak it in?

I know I wish I hadn't waited so long to come. They helped me a bunch right off. I was still unclear about what to do for a few meetings, but then I started asking questions that others didn't ask, getting several opinions, or having the answers repeated. It helped me get on with the program of feeling good about how to live with MY problems.

Just being around others helps. Sometimes a newcomer can become impatient because they can't do the things they see others doing; however, they get reassurance that they will get better and they get ideas on how to do it.

Mental as well as physical well-being is the goal, and we may improve the former by giving or receiving a pep talk, a hug, a shared good experience, a discussion of a problem, or sometimes just through the social interaction. This can relieve worries. We share positive ideas and experiences and try to instill a positive outlook and hope in one another. We have a unique problem inherent to each of us, but at the same time to the group.

Maybe just one little something someone says will make a world of difference. For example, a simple task for someone who has had their TEP for two or three years could be a real labor to a new TEP user. A hint to a new Servox user can help them to be understood. Little things mean a lot in such cases as we learn from each other.

Sometimes we discuss specific problems or updates on others who may be having problems with their health. We are constantly aware that the fight against cancer is far from over for some of us, but we can't and don't dwell on it. Stress management is a subtle factor since we do laugh and joke and relieve tension, but at the same time we talk about prevention and nutrition.

I think some key things are:

Awareness of the needs of others,

Education in helping others understand,

Intervention if asked for help or advice,

Prevention of possible problems before they arise,

Help in dealing with stress.

The basic support group is a group of people with similar interests working together for a common goal. In our cancer support group, we share a vision to find better, easier, and simpler ways to get and maintain a degree of good health.

Scotty's article gives us a good idea of what a support group should be, and the one we had was great for a few years. Over time, we lost members as they got well or went back to work. Since our meetings were at the clinic at 10AM, it was a bad time for many people. Other members had recurrences and could no longer travel. We lost both caregivers and patients when some of them died. Most of all, we struggled with getting new members when the government came up with new regulations about hospital privacy concerns and we stopped getting so many referrals for the new laryngectomees.

UAB was performing a large number of laryngectomy surgeries but many patients were from out of town, people who came here for their surgery and went home to a local hospital if they needed radiation treatments. Other clubs started up closer to their homes, and gas prices went sky high.

If that wasn't enough to reduce our membership, there were online sites where questions could be asked and answered, and if you had a computer you could save

both money and time by staying home and writing in. When a club gets so small that you can't ask speakers to come talk to you, it’s hard to hold it together. We lasted longer than most, and the HeadLines newsletter helped to hold us together longer.

Chapter Thirteen
HeadLines Newsletter, January 1996

During our January support group meeting, one of our fellow laryngectomees suggested that our group needed a newsletter and that, with my computer and my enthusiasm, I would be the ideal person to start one. He agreed to help by writing for it and I said I would come up with something to get us started, but I would rely on everyone to contribute.

The newsletter, HeadLines, started with the announcement of the next meeting, a description of what we wanted to do, and requests for help. I added some simple hints for humidifying that are just as true today as they were then:

1. Many of our winter problems are caused by a lack of humidity, so be sure to have a humidifier by your bed. Breathing the moist air can relieve mucus and cough.

2. A small atomizer filled with clean water can be used to spray your stoma cover when you are in an area where you can't control the humidity, such as in your automobile or in a room where you don't have a humidifier.

3. Wear your stoma bib. It helps to catch and hold moisture as you breathe. If you're raking leaves, woodworking, vacuuming, or anything that raises dust, dampen your bib so it will clean the air for you.

4. You may purchase foam filters for use with or without appliances. There is a new one for indwelling that you can change once a day. One of our members says he has hardly coughed since he began using it.

5. Drink lots of water.

(Author's Note: You will see a lot of references to moisture in this book. A humidifier is a must! A humidifier puts moisture in the air. So does a kettle boiling on the stove. I personally like having this machine in the winter when the indoor air is dry, but be aware that if you're on a tight budget and face the costs of medication, it's not important to spend $200 for a humidifier or to have a whole house unit. You can put the kettle on the stove or buy a simple humidifier at the drug store for less than twenty

dollars. It puts the same humidity (water) in the air as the $200 one. The cheaper one may not be as pretty or have as many settings, but they both have to be cleaned and refilled and they both work.

If you have the money, then this isn't a problem. Buy the one you like the best. If your humidity in your home is low even with a humidifier running, you should add humidity to the stoma area because the house doesn't need as much humidity as your trachea does. Wearing a damp stoma cover in addition to the basics will up the moisture content of the air you're breathing.

Be aware that new larys whose bodies are not accustomed to the new way of breathing need more moisture than old timers. When we old timers say, "I don't bother with that," you may need to "bother" with it at your stage of recovery.

HMEs (humidifiers) came along and provide an excellent way of keeping your respiratory system with enough moisture.

It might even be covered by your insurance.

Several people mentioned at the next meeting that they were following the suggestions. This gave us the direction our newsletter needed to go, which was to offer helpful hints interspersed with personal stories. We planned to publish articles that educated and encouraged. Some were written by caregivers and told of their loved ones' struggles with cancer, and some told their own story of adjustment. When the copy was ready, I would take it to our local chapter of the American Cancer Society, who agreed to take care of the printing, addressing, and mailing.

Learning to communicate with our families was one of the early items when we asked for helpful hints. Communication is a two-way street and often we're expected to call out from another room or speak to someone's back. We've always done this, but things have changed. We need face-to-face conversation because our expressions, a nod of the head, or pointing may help to get a message across more easily. When people turn their ears toward us, thinking to hear better, they lose the natural lip reading ability that we all have. Early on, a favorite expression of yours might be, "Look at me!"

As people, we have always communicated across a crowded room with a nod of the head or a movement of the thumb in the direction of the door. Now, we need even more of this personal sign language. In a crowded store or at a party, it helps us if our partners wear something bright so that we can find them with a glance.

Remember, we can't call out as loudly as we used to so we need some signs to reach out. We can't speak well enough to ask easily strangers where someone is.

Noise is a factor in our lives that needs to be controlled. We can no longer talk over televisions and radios, and we need to get in the habit of turning the volume down before we speak. The confusion of sounds coming from more than one direction can make it very difficult to find the words.

The telephone presents special problems. Instead of immediately launching into what we wish to ask, we should start with a sentence that gives the other person a chance to realize that they need to pay special attention.

At first, it's not out of line to ask, "Do you understand me?" and later, you might just say, "I need to get some information about..." or, "Would you be able to help me with this?" Speak slowly and distinctly. Once others get tuned in to your sound, you can be more natural. Most of us tend to keep the electrolarynx going when we are learning and it's much clearer to others if we phrase our sentences with breaks in the buzzing sound. Otherwise, we sound like a rambling paragraph without any punctuation.

It's hard to believe when we're going through a painful and scary time that later we will think back and be amazed at the difficulty we have in remembering all the details. At the time it's happening, we think, "I will never forget this as long as I live!"

In June of 1996, I wrote about some of the fears and problems of being a new laryngectomee. I visited a post-surgery "member of our club" in the hospital to give

a few hints on the use of the Servox and to answer questions.

Sometimes it's hard for us to hear the right question. Her daughter was asking all about the coughing and I answered every question carefully. Yes, we do cough up bloody mucus and yes, we do this for a long time. We gradually get better until it is not a problem anymore. Irrigation still causes us to cough but it's necessary to keep any mucus thinned and to help wash out pollens and other irritants.

Finally, she asked the question she had wanted to know from the beginning, "Does it still hurt so much to cough?" and I was able to give her the right answer. I had not been perceptive enough to hear that question at first because a year dulls the memory, not only of the coughing but of the fear of hurting while coughing.

My second reminder was from an email correspondent from England who was telling me how he built a shower protector for his stoma. Thinking back, I realized the process of nervously strapping on the shield before even stepping into the shower gave way to using it only when I was going to wash my hair. Then I left it off entirely and the only time I gave it a thought was when I avoided getting soap or too much water spray into my stoma, which I did by simply cupping my hand over the area or using a finger to occlude when I faced the water.

The pain, discomfort, and awkwardness have faded from memory. Aren't we lucky that it works that way!

Chapter Fourteen
Communication

In 1995, just after my surgery, I searched for help, turning as I had all of my life to the public library. The only book I could find written for or by a laryngectomee was out of print, but I found it in the library. It was written by the actor, William Gargan, who had a laryngectomy in 1960.

I was horrified by his beliefs and what he told others. He bragged about taking an electronic larynx away from a new patient and telling him to learn to speak the "real" way. He was firm in his beliefs that every laryngectomee could speak with esophageal speech or they were just not trying. I was just learning to put together my electronic voice and I hated what he was saying. It took away any individual choice.

His was the opposite of my belief that any method that gets you communicating is a good voice for you. You may be able to learn to speak via esophageal, tracheoesophageal (TEP), or electrolarynx, and more power to those who do learn more than one method. I have heard many great speakers from each way. We had a visitor to our local club who used buccal speech, which is produced from air between the cheek and teeth, now called Donald Duck speech because everyone immediately recognizes that sound.

This lady was young, had no formal speech training, and raised her family with no problems. The kids understood everything she said and her life was

fine. Even though other kinds of speech were offered later, she had no interest in speaking another way. It was my first connection with someone who really had been self-taught and had made her voice be what she had available at that time.

Most of us also learn what signals work. We learn as a baby to point to what we need. We learn that to keep something away from us, we throw up a hand with the palm outward and pull the body away. We know how to signal okay or no. Hand signals are not complete in themselves but they help a lot when you, as an adult, are learning to speak again. The main problem is getting people to look at you and I learned fast that favorite phrase of mine from that time: Look. At. Me.

A starting voice is almost always mouthing with no sound, pointing and signaling, shaking or nodding your head, but you need the people to look at you and some don't like to do that. I never realized how many people look away when you talk to them or even when they are speaking to you. They glance and then start a story looking over your shoulder. You can't even nod your head in agreement. It is as though communication is a one way street.

I see and play with apps for phones and pads. I have an iPhone but it is so much easier to use my iPad because the full sized keyboard gives my fingers more room. Each year, these programs get more plentiful and better sounding. These are great for patients who can sit up in bed after surgery, despite their tubes and drains, because they can use their iPad text to speech program to tell their doctor or nurse exactly where they hurt or what they need to know. It is frustrating to try to find out

something, and your doctor, who has to get to other patients, is gone before you can find a way to ask it so he understands.

New patients now get to type normal questions about home and family to ask their caregiver so they do not have struggle to scribble from an uncomfortable position. I tried to write my questions with a pencil and paper in advance but I could never find the one page I wanted among the clutter of used notes covering the bed.

It is less frustrating now, and you can be ready to have the text selected for the next person to come through the door. You can even write your own phrases and keep one handy that says, "I have no voice." Save it, and you will use it. Maybe play it for that nurse who answers your room call with a question. Turn up the volume and let your iPad do the work.

If your family is there, you can type an answer to what they are saying and when they finish, hit “speak” and give your opinion. It’s not perfect but it removes some of the frustration of trying to signal an answer, especially when you’re still connected to an IV.

In 1998, I developed a sample letter-sized chart with many common requests printed on it. These are items needed by a hospitalized laryngetomee so the patient could point to let anyone know what was needed.

Are you too cold or too hot, need a trip to the bathroom, or need to clean your stoma? Point to the word on the chart. On the back of it, there is a list of items you might need your caregiver to find for you, such as a comb or washcloth, and an alphabet so you could spell out a word.

After I had a sample chart, I wrote to the head of InHealth Technologies and offered it to her free, as long as it was a giveaway item. She accepted, and we reworked it a few times over the years but it has remained a sturdy, bright yellow card, laminated in plastic, with the basic needs on it. It's printed in both English and Spanish. They even contacted me at one time for permission to allow the Chinese to use it and change to their language. It's free upon request and my copyright is still there.

By March 1999, stocks of charts were in place. My notices were published in the WebWhispers email distribution list and in the Larynx-C listserv that these cards were now available free through a telephone call to the InHealth service desk and would be given out at the 1999 IAL Annual Meeting/Voice Institute in Reno.

I had been a laryngectomee exactly four years and I was so excited every year to see my chart being shared with everyone at the IAL Annual Meeting.

Chapter Fifteen
Voice Choices

I used a Servox for well over a year and it gave me the opportunity to learn how effective speech could be if you used careful enunciation and spacing, and how ineffective it could be if you slurred words and ran one sound into the next without control.

The electrolarynx is one of the voice choices you can make. It provides the vibration needed to turn silence into words. It could be used with an oral adapter right after surgery, but some healing needs to take place before it's comfortable to use it under the neck.

Many people rebelled against this method of speaking because they did not like the buzzing sound. At this point, they needed to learn that a voice of any kind that could be understood was much more important to the family than no words at all.

Finally, in August 1996, I made the decision to try for the TEP and I wrote another group letter so everyone would know what I was planning.

Dear Friends and Family,

Been a long time since I have written one of these group letters, but then, I haven't had many changes. I have gradually gotten better, have had good checkups by everybody, and finally received the OK for the additional surgery that we had hoped to do a year ago. I will be going to same day

surgery on the 22nd of August, and the following is a description of what will be happening:

You know that the esophagus and trachea are separate on a laryngectomee, the former going mouth to stomach and the latter from neck stoma to lungs, but they are parallel near the point where the trachea takes the turn outward to make the stoma. The surgery they are going to do is to make a puncture between the two, and the appliance they are going to install is a prosthesis, a tube with a flange at either end to help it stay in place. In the esophageal side is a one-way valve that will let air up the prosthesis and into the esophagus, giving me air to talk but keeping liquids from coming back through the wrong way. The vibrations of the throat should give me sound, which I will shape in the regular manner of talking. Tonal qualities are missing. Vocal cords normally control that. In my case, I will use my finger or thumb to put over my stoma when I am ready to redirect the exhaled lung air for talking.

I will have the puncture made on the 22nd and they will put a plug in it while it heals. Then I will go back the next week to have the prosthesis put in and to try sounds. They tell me that learning to talk this way is a matter of practice, practice, practice. Part of it is learning breath control and to be comfortable with that. I have heard one lady who speaks in a whisper, and another who has so much mucus she has constant problems, but there are others who sound really great. I will keep my trusty Servox near me for when I have problems,

or to be able to answer the telephone if I have my prosthesis out to clean, so I'll have two voices.

Love to all of you, Pat

I have put together excerpts from my personal writing that tell how much I was learning as it was happening. It can give you some insight into how I was adjusting to the TEP.

Today I went to Scott's, where we worked for about two hours cutting some holes into a couple of different kinds of vents so I can wear the vent in my stoma (stopping it from shrinking again), and still get air to the prosthesis. These will probably not be the final product, but they work! I need to practice and get the feel of how to deal with the mucus and airflow, which sometimes cuts off in the middle of a word.

Everybody who has a TEP has to learn to talk again, but the problems are different for each person and I think I got a goodly share of additional things to deal with over a short period of time. At least mine were not the type that meant I could never talk. I know this is going to work.

I was awake in the middle of the night. Watched a little TV, read, and then went back to sleep. Didn't get up till 8:30. I nervously squirted water through the prosthesis and put the new vent in, the one with the hole in it. Nancy knew that I was going to cut a hole in it, but she probably

didn't mean for me to do this the way we did. We ended up with a hole that the prosthesis sticks through. I have to carefully get it unhooked before removing it, which is a little touchy. Anyway, I got all ready and tried my voice, and it was there!

I still think breath control is the secret. With the Servox, I hold my breath when I talk. Now I need to breathe steadily outward as I talk, and for now breathe in between phrases. When I try to take a big breath and breathe out, it stops. The pressure is too great.

Maybe I'll learn how to control that later, but for now I'll just try to be a little breathy. Me and Marilyn Monroe! I used to sound like Tallulah or Lauren Bacall. Now I sound like Jimmy Durante! At least, I don't look like him...but can you picture June Allyson with Jimmy Durante's voice!

I find that I sound better in the morning or middle of the day. When I'm tired, as I am today, I don't talk as well. I was asked what I mean by “occlude.” It means to close a passageway, which in my case, is done by putting a finger over my stoma when I breathe out in order to allow the air to go up through the prosthesis into my throat. I used to hold the Servox with my right hand and press the button with my thumb, so over a period of time, my right shoulder gave me all kinds of trouble (of course, that was my breast surgery side, too).

Now I put my left hand flat against my upper chest on the left hand side so that my middle finger comes to the hollow of my throat. That’s the position I use to talk,

merely moving my finger out when I breathe in and dropping it over my stoma to seal it when I talk.

It’s just a little higher than the typical Southern Belle, saying, "Oh, my, I think I'm going to have heart palpitations." That position!

There is an automatic valve that a lot of people use and I may decide to try that later, but it’s bulky and requires gluing a big ring around the stoma. My skin shudders at the thought since trying to take the ring off took some skin with it and this needs to be done daily. Also, the mucus built up inside the ring and I wasn’t able to clean it properly until I took the ring off.

Dr. Peters asked if I was interested in going to the automatic valve. I told him not right now and explained all of the skin and mucus reasons. He agreed that it was not perfect, although many people use it well, with the main complaint being the accumulation of mucus. The valve does open and close automatically as you push air out to talk, and the benefit is you can talk with your hands free. I could be chopping vegetables and answer on the speakerphone from the counter in the kitchen. That would be handy. If they improve the valve and make it lighter and easier to remove to clean, I would be interested. For now, I have my new play toy that lets me talk. It is enough.

I was learning to talk, but I couldn’t hear myself talk. I would think something was very clear, but it was not always so. I got the portable cassette recorder out and sat it on the dining room table along with a book that had lists of words and phrases. It was a lot of work to keep

trying the same phrases over and over, all while listening then trying again.

Chapter Sixteen
Sipping and Swallowing

Many patients have difficulties swallowing and they never understand why. The professional and lay people who are helping you are often busy taking care of warnings about voicing and teaching you how to take care of your surgical site, clean your stoma, and telling you what you cannot do any more. How to live with daily problems is often left to learn on your own or from other laryngectomees.

No one ever warned me that when I got home and was able to sip and swallow liquid that a big gulp of liquid wouldn't work. My new throat construction is now a passage going from my mouth directly to my stomach. After the surgery, I was left with a smaller esophagus and some swelling that had not yet gone down yet.

I learned by experimenting. A little sip would go down without a problem, but when I tried to gulp a drink, which I did thoughtlessly, there was not enough room for it to pass down the esophagus. In a normal swallowing motion, the tongue blocks the liquid from coming back up into the mouth, so where does the liquid go? Out the nose! So sip and swallow is the rule.

I had the same lovely (and accidental) nasal wash when I leaned over to put food and water down for my cats right after I fed myself one evening. Lesson learned. When I leaned over, the liquid contents of my stomach and esophagus poured upward like the spout of a pitcher. This is not like vomiting, it's simply tilting a pitcher and

smoothly pouring out the spout, which is now your nose. The solution for me was simple. Feed the cats first. I couldn't change it, so I had to adapt.

When I had asked Dr.Peters about this, he wrote to answer me this way:

Let’s talk about this reflux thing for a minute. Under normal circumstances, there are two muscular bands or sphincters in the esophagus which prevent reflux. One is located where the esophagus joins the stomach and the other is located behind the larynx at the beginning of the esophagus in the neck. The lower esophageal sphincter (LES) often becomes compromised when there is a hiatal hernia, a condition resulting from a weakness in the diaphragm, which allows the stomach to slip up from the abdomen into the lower chest cavity. When this happens you get what is known as gastroesophageal reflux- the condition we all hear so much about in the media these days. The other sphincter, the cricopharyngeus or the upper esophageal sphincter (UES) prevents things from coming up the esophagus into the throat and mouth. This muscular ring takes its origin from the lower part of the larynx, a part called the cricoid cartilage. But guess what —you ain’t got one no more! Your cricoid was taken out when your larynx was removed. This leaves the upper part of your esophagus sort of flaccid and always open, and this could result in the reflux of stomach contents up into your throat and mouth. About 80% of the general adult population has a hiatal hernia. So if you have a hiatal hernia and, in addition have had a laryngectomy, then you get a double whammy.

So what’s a guy/girl to do? Gastroesophageal reflux is usually managed with medicine to stop the stomach

from making acid, along with dietary and lifestyle modifications. Severe cases may require surgery to keep the stomach from slipping up into the chest. Taking care of reflux from the UES is more problematic, however. Simply knowing that this is a problem and its cause are probably the most important things. Avoid bending over when you have a full stomach after meals. You may also might try reducing the size of each individual meal and eat four or five times a day instead of the usual three.

Chapter Seventeen
Helpful Hints for Eating Out

I wrote this chapter so I can share with you a few items from my own experiences and those of my friends.

I never order anything that will be hard to chew unless I plan to eat the other items on my plate and take that one home. I have seen laryngectomees order a to-go box to be brought first and filled from their plates when it arrives, leaving a nice small meal.

Sometimes you get surprised at how well something goes down, but when I'm eating out I do not even consider foods that are dry. Sauces and gravies are a laryngectomee's friend. Soup is mostly very easy for us to eat. Some salads are easy, but ones with big chunks of raw vegetables are better eaten at home. Sometimes we expect too much from soft foods and accidentally take bigger bites. Not a good idea, as small bites are wiser.

When you eat out, sit up and keep your neck straightened upward to keep your inside passage as open as possible. We tend to lean forward and jut our chins out to make it easier to use the EL or to occlude, but you don't want to do that when you're eating.

A quick note about speaking while eating out: When you are new, it's helpful to plan for your voice not being understood or heard in a crowded restaurant. Have a writing pad and pencil nearby, or one of those small boards that you can write and erase.

Since text to speech programs are now excellent, I always take my iPad or iPhone. I have several apps that will speak for me. I type and touch “speak,” and it does.

Restaurants where you are ordering from a menu are easier since usually you can point to what you want on the menu. If I am going to go to a counter to order, I ask my companion to hang near me because I may need someone to call it out over the counter. They didn't make these places friendly for those who cannot speak clearly or loudly.

Always order a glass of water in addition to your regular drink if they don't bring you one. You might need it to sip or to moisten your mouth to chew your food.

You might think that buffets are easier, but be careful. If you’re going to try the buffet line, be assured that someone will speak to you. I have learned to smile and shake or nod my head. It’s better than trying to find a place to put your plate down in order to use your EL if you’re standing with salad in one hand and a dinner plate in the other.

At a buffet, I would suggest you go first and get your drink and salad or soup, take it to the table, then return to get the dinner plate. I prefer to have soup first and then get hot foods. Soup is also a dish that goes down easier and faster than other foods.

Serving ourselves at a buffet calls for finesse. Think of it this way: have you ever seen people reach over and pick up food with their fingers, eat it while in line, lick their fingers, and then start serving their plate by picking up a spoon with the same hand? It’s not very appetizing, is it?

We don't want people to do that, so be careful in a buffet line about using the same hand to occlude your stoma, and then reach for serving piece. Most people have never seen a stoma and do not need to have their first view of one while they're in line for food. Take care that no one goes away thinking worse of any one of us, because whether or not we mean to, we represent each other.

When I go to the local neighborhood Chinese restaurant, I know that going early gives me a choice of tables in a quiet atmosphere where I can order easily. I'll have some hot soup which relaxes my throat, and an eggroll that I will have time to finish before the dinner is served. If I am having lunch alone, I bring a book and a small folding bookrack, and I prop it up to read as I take my time.

In the few first years, I would get coughing spells and that was difficult. It's better to have a friend with you so you can leave the table, since your friend can be sure your table is not cleared while you get your coughing spell over in privacy.

Eating out alone or with others does become easier as we learn to deal with the differences and plan for them.

Chapter Eighteen
Let's Talk Dilation

Sometimes as I sit on the sidelines, I hear complaints about a problem, or see people accepting their issues. Some people get their difficulties resolved, while others are never satisfied with the fact that things are not like they used to be.

It makes me wonder how medical professionals react when each of those people come in for a checkup and say they are having trouble swallowing. Some define difficulty swallowing as not being able to eat the way they used to and accept the instant gratification of having the esophagus stretched. Some are having trouble getting any kind of food down and desperately need a bigger opening for food to go through, and even a slightly bigger opening works. Some need a tube to get enough nourishment. So we go from slight discomfort to desperate need.

I think the doctors and SLPs should tell us something like this: you may expect to have some difficulty swallowing, so don't gulp or swallow without chewing well and taking liquid with it. Slow down and enjoy each bite so you get in less trouble.

For the folks who write in to our list to ask others about getting a dilation, we sometimes get answers with rave reviews of the successful stretch and the ease of eating again. Some say they go regularly to have this done and you may be thinking this is some kind of cure.

This is not a cure. It is a treatment that can be go on for years with multiple repeats.

One letter like this one from the list makes you stop and think:

"Don't do the dilation unless absolutely necessary. I had this done a couple of times with no issues then on the next try my esophagus was perforated and that was a huge problem. I was in ICU for 2 1/2 weeks and it was a mess."

Another letter from Hank Luniewski, one of our members, reads:

There were a lot of emails on dilations recently, but one aspect was not mentioned. I have had two different types of esophageal dilations; one type is performed by the gastroenterology group. It consists of a balloon type of dilation. I found that in my case it was not very effective.

The second type of dilation is performed by the ENT surgeon and is an expanding rod type of dilation. After trying the balloon type twice, I was given this rod type recently. In my case, this method turned out to be much more effective. My esophagus was initially measured to be in the high 30s French. For those of you who don't know, 1 unit of French equals 1/3 mm. Or conversely, 1 mm equals 3 French. Anyway, they were able to dilate me to 46 French. The goal for a normal dilation is 60 French.

As a result of this latest dilation, the diverticulum (pouch) that I had in my esophagus was mostly eliminated. Plus, I did find eating to be a little less difficult. I don't know if the esophagus will want to narrow with time, or not. We shall see. As always, we hope for the best, right?

Hank Luniewski

I looked up the National Institute of Health explanation of the sizes and they say: "Solid food dysphagia occurs with an esophageal lumen less than 13 mm. In general, dilation up to 18 mm (54 Fr) will allow a regular diet to be consumed. In reality though, many patients will be able to eat a fairly normal diet after the passage of a 16 mm (48 Fr) dilator. It is important to instruct patients to chew their food well until they are dilated up to at least 16 mm."

After reading about so many people who were pleased and the few who had surgery after dilation problems, my advice is basic: you don't want to have that done unless you really need it. There is always the chance of perforation or of stretching the scar tissue a little further than it wants to go. Talk to your doctor about the concerns. I would not want one who would gamble to take it just a little further. When you get a tear, is not like you can just not go that far again. Your days of dilations are likely over and possible surgery is ahead.

My suggestion for making your choice is common sense. Try everything else first to be sure it isn't irritation in the throat from acid reflux, yeast, or throat irritation from other things that can cause swelling in the tissues. Watch your diet for anything that can burn your throat.

Some days when it’s allergy season, I have to eat softer food, eat more slowly, and take even smaller bites. My throat is swollen and I need to look at the cause instead of the result and treat the right thing.

A yeast problem in the throat can cause some swelling, thicker saliva, and bubbles from the yeast that clog up the works, making it difficult to swallow. Acid reflux is also a common cause of swallowing problems and just taking a medication doesn't mean you’re doing all you can to make it better.

Dental problems can even cause trouble swallowing. If you can chew better, you might find you swallow better. I had to have some crowns a couple of years ago, and was amazed at the difference it made in getting a better bite again.

Chapter Nineteen
Going Back to Work

Many of our WebWhispers members want to go back to work. Being able to do so depends on several things, including your health, your communication skills in relation to the job, the kind of work you were doing or want to do now, how understanding your bosses and company are about your abilities, and how long you have left to work before retirement

We have teachers who went back to teaching with a new voice and sales people who had great success after laryngectomy. We have doctors, nurses, lawyers, bookkeepers, computer personnel, factory workers, tree men, retail clerks, and traveling representatives. If you are able to speak and be understood with any type of speech, it is an advantage.

Some of the jobs that would be more difficult for us would be ones where there are fumes to deal with. Remember, we not only have a communication problem, but we are sometimes very sensitive to what we breathe. Going back to a job where you are exposed to chemical fumes might be very difficult and even dangerous for you.

At the same time, you may return to an office and find you are next to the desk of someone who uses far too much perfume or shaving lotion. That may bother you to the extent of not being able to continue. There was a time

when some work places still allowed smoking. That is especially bad for neck breathers.

You might find that you are able to work, but not at the same job you had before. It is more likely that you will be accepted back where they know you, but many of us do find work at new jobs. It takes more time and you have to work at being the best you can be at new assignments or ways of doing them.

I am not an attorney, but there are laws that cover what needs to be offered in the way of a job. There are resources available, especially on the internet, that can point you to your workplace rights as a laryngectomee.

Chapter Twenty
Fishing, Boating, Swimming, and Cruising

Twenty years ago, almost every doctor would tell a new lary that you cannot ever go swimming again and that you would be a fool to go out even in a fishing boat, not to mention riding in a speed boat.

But for our WebWhispers online community annual get together one year, I suggested something new and different. I had picked up cruise brochures and found an inexpensive seven-day cruise in the Gulf for the next April, sailing out of New Orleans. I suggested that we set it up as something we sponsored, but did not pay for. I could prepare the information and sign us up, and the agent would take care of the deposits and payments, reservations, and questions from our newcomers to cruising.

Note: This would be a trial run to see if our people were interested in traveling together. It would be a WW social activity to encourage our members to get out, meet people, and learn to socialize as laryngectomees.

That year, we had twenty-one people signed on for our first cruise, and I chose a tour in the Cayman Islands. We have continued to have cruises every year since and have them on our website for WebWhispers and friends.

When I advertised that we were sponsoring our first WebWhispers cruise, the reaction was funny, from shock to disbelief to questions. Finally a member in Texas wrote me a letter with a big SIGH! noted on it. He wrote, "I have been telling my wife for seven years that I

absolutely cannot go on the water, and you had to set up a cruise. I finally give up. Add reservations for two."

Of the twenty-one people on that cruise, thirteen of them were laryngectomees. We had a wonderful time and no one drowned! Since then we have set up a cruise to a different place every year. We included an activities area on our site which has all of the past cruises listed, including all of the information and a slide show of photos from each one. We found that people who would never have wanted to go alone had fun with us and they were not "different."

On some of the tours at the ports, the ones who wanted to go signed up for boat rides or group tours, and we've also had tours where we had our own bus. We learned from this how to be social with others who might start out staring. Sometimes as we were in line to get on shore, one of us would speak with an EL, which carries the sound. A few people in line in front of us would turn to see what they were hearing, and the next minute one of them would wave enthusiastically because they had met us the night before. Having these experiences took away the sting of what we had sometimes misunderstood as a critical look. Our shy ones and even the angry ones learned to be social again.

On the boat, we went by our own schedule for breakfast and lunch but met at our tables for dinner. It was comfortable to eat our big meal of the day with folks who understood that we usually took a longer time and we warned our waiters in advance.

Aboard the cruises now, we know that they will blend food and bring it to the table or prepare special dishes if needed. Ships' menus are very well planned and

they now mark the dishes for a heart menu, diabetic, and even gluten-free dishes. We have even had travelers who had liquid food delivered to their cabins, just like their oxygen. Most of the companies have that service if you know to ask for it.

We are planning to go to Alaska in 2014 and possibly eastern Canada in 2015, but we always try to get input from the group on where everyone wants to travel. When the arrangements are settled, they'll be on our cruise page under Activities on WebWhispers.org.

As for our personal safety due to stomas, many of us still fish or enjoy small boating, but we just have to be careful. There are special vests that can hold the person up out of the water for the six or eight inches needed to get the stoma above the water line. There is information about them on our site in the section of the library called, "How We Live – Swimming."

Chapter Twenty-One
Depression

I remember reading about a study that links poverty and a mother's depression. It was a very expensive study to prove that mothers who live in poverty are more likely to be depressed, and raise children who are more likely to have child development problems.

This is news? They point out that these moms lie in bed so depressed that they can't take care of their children's physical needs.

Again, this is unexpected? While they're at it, why not check on the mom who is trying to get three children fed, dressed, and ready for school so she can get to work and earn the money to buy food and pay the school expenses? Oops, wrong study. What is there that's so fascinating about a study that proves what we would already know if we have any common sense at all?

So let's do a quick study on depression after laryngectomy.

You have cancer. Is it normal to find that depressing? Yes. You need serious surgery that is going to change a lot of your life. Scary? Yes. You are going to lose the voice you have always had. Depressing? Yes. You may have some difficulties with tasting, chewing, swallowing, and the ability to smell. Depressed enough? You now have a pillow over your head and are trying not to hear anymore, aren't you?

Even more frightening is getting through the surgery and finding out you still face radiation. All the fears you've had about this treatment spring up and choke out any relief you felt from having gotten through the surgery. What causes your depression?

Everything. Maybe the complexity of the problems is just too much to handle all at one time. If you have everything coming at you at one time, try to handle one thing at a time. Deal with today whenever possible. Or maybe you're too tired to work it out right now. So don't try to figure out what causes it. Just talk about what you can do that may help.

Ask your doctor to run a thyroid test. If your thyroid was damaged by the surgery, radiation, or chemo, you could be hypothyroid. Big symptoms of this are fatigue, confusion, depression, dry skin, hair, and nails, and puffiness from water retention.

It's very common for people not to recognize the symptoms. If we haven't been told to be checked every year or that a particular combination of symptoms may be a thyroid problem, we're likely to blame fatigue on other things: aftereffects of anesthesia from surgery, multiple surgeries that have kept you weak and tired, loss of sleep, hopelessness at all of the physical changes, too much to do, or just overdoing it.

You might think, "I'm so tired, I just can't think straight today," and yet still overlook it on a list of symptoms because those other problems are more obvious. You think that's why you are tired all the time. It may be mental, physical, or emotional, but a thorough checkup to see what's wrong would be in order, including a thyroid check.

Many laryngectomees or throat cancer patients have totally changed their lives by restoring or replacing their thyroid function. One pill a day can take care of a lot of problems if your thyroid numbers are off. A simple blood test at intervals will be able to find the level of therapy you need.

I did some research on common depression felt by people who are not physically ill but have a dark cloud that affects their ability to be happy or content. Every website I found promotes exercise at or near the top of the list of treatments. They're not asking that you spend hours a day or do any particular exercise, but each expert suggests about twenty to thirty minutes a day of doing something that gets you moving five to seven days a week.

Now the last thing I ever wanted to do was exercise, but the experts say it releases "feel good" chemicals in your brain. My first thought was that I don't workout hard enough to do that. But this year, I did feel better about myself whenever I rode my stationary bike, walked up the stairs instead of taking an elevator, or parked further out at the store and walked half the length of the parking lot. I know it's good for my body and my mind, but being proud of something you've done raises a level of self-appreciation that helps fights depression.

It's not a good idea to try to do more faster, though. As laryngectomees, we tend to get out of breath, get more mucus, cough, and have to stop to take care of that. Start slow and find your own level of comfort. Most of all, be proud of what you do.

Once you get checked by the doctor, you'll know you can exercise some. You can also find some other

things to take pleasure in, such as your grandchildren, walking with your dog, curling up with your cat and reading a good book, finding something you really like and look forward to on the TV, getting a massage, enjoying your mate or friends and family.

Then give yourself some time. If you are low and miserable about everything, then tell your doctor and see if you can get the proper medication to help you handle what you need to do.

Chapter Twenty-Two
Acceptance & Relationships

Social activities may change after your surgery. Learning to outtalk a friend's voice, speak over a restaurant's music, or to talk over the TV at someone's home may be a bit more than your new voice is able to do. Most of us are accustomed to having noise everywhere, all the time, and it's okay when you have the control button to turn it down.

But when you're in an automobile or on the street with traffic noise, it's hard to raise your voice. Even if you can speak up, you'll likely strain too much trying. ELs are handy for raising the level of your voice, but that requires batteries and can call a lot of attention to the odd sounding voice.

It also can be embarrassing if you flip up the dial on your EL and then all of a sudden, you're the only one in the room speaking. The others all stop to look for the strange noise. From past experience, I can suggest you just let it happen, wave your hand with the EL, and speak with it, saying, "It's my new voice. I'm just learning!" Then lower the volume and turn back to your own table.

Don't get upset if people look. It's human nature. If the sound is loud or constant, people might look to see if it's a kid with a new toy but when they see it's an adult with a new voice, they see it differently.

After my surgery, I was not ready to go to any parties other than small groups with my immediate family. I was concerned about having difficulty with

talking but I didn't realize there would be people who would be more uncomfortable with me than I was. When a close friend who managed a nearby apartment community invited me to a Christmas brunch, I decided it was time I plow ahead with my socializing.

The year before, I had been in the process of starting a second round of radiation treatments and had missed the party. This time, it took courage to tackle a group of mixed friends and strangers, especially one this large, but I was determined to be as much like my old self as possible. A number of people greeted me warmly as I arrived wearing my bright green shirt decorated with white cats in Santa hats. They told me how great I looked, and commented how much they had missed me. The buzz of the Servox attracted eyes from around the room and a few people openly looked away as they saw me glance at them. I had already had enough experience with meeting strangers to realize they thought they wouldn't be able to understand me and didn't want to be embarrassed. At least, that is what I believe.

I headed for the buffet where there were huge bowls of fruit salad, a wonderful egg casserole, sausages and ham, biscuits and gravy, jellies and jams, coffee cakes, and cheese grits...a real Southern delicacy!

Carrying a generous helping, I took a table for six that was just being vacated and shortly thereafter watched a group of four head for my table and stop. They whispered for a moment, glanced over again, and turned to look for another place. There were no other tables available. After several awkward starts, they managed to fit themselves into a love seat with one person propped on each arm. They had plates balanced

precariously and were in a location where people were constantly squeezing by. It was obvious that these people were avoiding contact with something they didn't know how to deal with, but at that moment, my table seemed to be banquet-sized in its emptiness.

I was joined first by a man who headed directly for my table, introduced himself, and told me that he had just explained to two boys at the buffet why I talked the way I do. The boys were curious and had been staring. We were joined by two of my close friends who had just arrived, and then by a young woman who had recently moved to Alabama. Her father, who was from Minnesota, was visiting for the Christmas season and joined us. It was fun watching him try the cheese grits for the first time!

My hurt feelings faded away, along with the unshed tears of self-pity. The people who chose to sit elsewhere should have eavesdropped on our table because we had a lively, interesting conversation going about cancer, being single, getting married, moving South, and even computers and internet service providers. We were an entertaining, fun group, and it turned into a delightful day.

A few weeks after that, I went to a different kind of Christmas party. This one was for the Kirklin Clinic Head and Neck Cancer Support Group. There were over twenty members of our group there and we brought family members of all ages. No matter how well or how poorly we were able to communicate, we each took the floor to introduce ourselves and talk a little. Sometimes a family member had to take over this introduction. Being so newly involved with an online group, I talked about

communicating by computer and told them of the information and compassion I had found on the Compuserve Cancer Forum. In fact, I talked so much that they teased me about running my Servox battery down and wanted to know if I had brought an extra. I immediately held up two fingers and got a laugh.

The family members talked with each other and with us in complete comfort. The ones who were there with relatives but were not talking yet asked questions by writing, signaling, and through the people who came with them. They paid attention to what we did and how we did it. There was an atmosphere of love and caring in this small group of men and women, black and white, young and old. There were no differences between us and we were locked into sharing a mutual problem.

Having been in charge of discussion groups years before for a large chapter of Parents Without Partners, I had heard many stories of broken and damaged marriages, but after having cancer twice, I saw over and over again what cancer does to families. It’s bad enough to face a deadly disease, but to have a mate who isn't supportive or doesn't know how to be is only one of the problems to face.

I was reminded of the problems of everyday living when I attended a pre-Thanksgiving dinner at a local support group associated with a hospital sixty miles from my home. I was just getting seated when a number of folks came in the door. A gentleman lary asked if I had arrived and he headed for me. I stood up and he introduced himself, took my hand, and just didn't let it go.

He said, "That article you wrote saved my marriage. Everything you wrote could have been me and my wife. You could have been standing outside our window watching us."

He added that he called his wife to come read this with him and said, "That's me, that's the way I feel." They talked about things they had never said to each other and why each had been resenting the other's attitude. They really talked openly. After the dinner, he came back to take me over to meet his wife and friends. The following is the article.

Emotional Byproducts of Cancer

Any major change in your life may create a shift in your relationships that requires far-reaching adjustments. Cancer is an extreme change and prolonged treatments seriously alter everything in your life. Those who come through this kind of crisis will sometimes find they do not feel the same as they did toward their partners.

The dependency balance may change. One of you may love the other even more, or maybe less. Likes and dislikes can change and the behavior of one may make the other respect them more for what they are capable of or less because their behavior under stress is not what was expected. If you must have a laryngectomy, ask yourself some tough questions about both sides of your relationship. You and your mate are the only ones who can answer these questions.

A professional marriage or relationship counselor can help with the stress and might allow each person to define problems that neither can discuss with the other, no matter how close a couple is or how much they love

each other. Fear of taking that big a step or the inability to speak of a problem can hurt the other person deeply. In some cases, it feels like everything has been said so many times and in so many ways that repeating it is useless. If that is the case, it can feel like you're screaming in the wind as your words are blown away.

My comments are not directed toward any one person's situation and I hope it is far removed from what you have experienced, but it might help some to understand a little of what could be going on with your own lives and partners. You and your caregiver might have had one or more of these problems. What changes have been necessary in everyday life since cancer joined the family?

FINANCIAL STRESS - Is the cancer patient still the wage earner? Is he trying to go back to work before he is ready because he feels like he has to? Did he have to change his type of work and take a lesser position due to his cancer? Is he now home permanently? Was he able to obtain disability income? Did the other person in the relationship work, and has that person had to be away from work to be with her husband, damaging her job security and earning ability? Has this cut the household income so both people are worried about finances? Or did one person have to go to work after years as a stay-at-home partner? Did she need job training to even get hired again? Did any of this change the financial balance of your lives?

EXTREME FATIGUE - Is the patient exhausted from the physical and emotional stress of the surgeries, radiation, or chemo, or from the sleeplessness caused by the coughing, pain, and discomfort? Is she exhausted

from the effort of listening and watching him, of being there when he needs something, of trying to understand and help him while she still tries to keep up with the everyday chores and a job?

CHANGING ATTITUDES - Is the patient resentful and angry that this happened to him, or is his loved one also feeling resentful and angry that this happened to her? Does he refuse to eat food she prepares, pay no attention to what the doctor says to do, or resists learning to talk again? Does she ignore him or does she feel it is her responsibility to get him well, and is she overbearing in trying to do too much and force him to do the same? Do these feelings surround and take over their lives? Do they love each other but each find the other unbelievably irritating?

SOCIAL - Are they staying at home and avoiding old friends? Are they able to eat out in public anymore? Do they watch mindless TV so they don't have to try to communicate? Do they no longer go to their religious services or have people over for dinner or to visit? Does he refuse to go out and is she afraid to leave him alone? Are they lonely together?

ANGER – Do they take out anger on each other? Are things left unsaid or is too much said? Do they lay blame because of smoking, drinking, or waiting too late to go to the doctor? Are they angry at the professionals because they were not saved from this or because they feel there had been a misdiagnosis? Is either of them bitter at life?

While any one of the above may or may not cause a loving relationship to dissolve, they can cause changes in the way one of them feels toward the other, their union,

and their lives. One or both may be thinking, “I don’t want to live like this the rest of my life,” or “What happened to the person I married?”

It’s natural to have some depression when you suffer the loss of your health (even for a short period of time) and it’s natural for this to affect both. One person can’t fix it alone. If these are problems that affect both of you, tackle them together, one problem at a time, before they grow insurmountable. Get some help from a professional counselor. That person may not be able to fix your job situation, but may be able to help you each deal with anger, hurt, frustration, and confusion. You can make one step in the right direction by treating your partner with respect and caring. Start now. Even the best of marriages or relationships can be damaged if you don’t deal with these emotional byproducts of cancer.

Chapter Twenty-Three
Retrospect

Many years ago, I traveled throughout Alabama as a company representative. I was the only woman in the national sales group so I was their only "salesperson." Funny, I'd always thought of salesman as one word describing an occupation, no matter who did the job, with no need to change the name. I was rather proud of being a salesman.

While traveling out of town, I was about 100 miles from home and found deep in the Alabama countryside a farm store that was quite large, having many services available to the locals. Not what they call brick and mortar, but graying weathered boards that looked like they had been there for many years. They were closed for lunch, as their hand painted sign announced, and the hours for working were listed from early morning to late afternoon, Monday through Friday. Saturday was added later, as you could tell from the paint and style, followed by one word for the hours: Depends.

I have always wished I had picture of that sign. If so, it would be on the wall right above where my computer is. Everything we do or believe is dependent on other people and happenings. So the answer to almost everything is: depends.

Through the years of getting to know many laryngectomee patients, there are examples for any point you wish to prove. The length of time for surgery, for

healing, for returning to work, for retiring, and for learning to talk again are all subjects discussed frequently, but which of the answers will apply to you? Depends.

It depends on your cancer, your general health, how well you respond to the surgery or treatment, your doctor and his training and beliefs. Each of these can be split into many subtopics that make you different from other patients.

Those of us who found each other online were exposed to many differences in what treatments we had and what we were told about our new situations. It was a fascinating experience to find the differences.

I am a great believer in education, and I believe you must know what has happened to you and how to deal with it for rehabilitation. I am constantly involved. I work harder than I did when I got paid for it, writing messages and articles, editing a newsletter, running meetings, attending others, making speeches, calling on patients. Being a lary helps me understand the people I work for and associate with. I love learning from my friends in my local support group and members of the support groups online. Sometimes I feel that we might even qualify our answers too much with constant warnings that we are different or recommendations to see your doctor, but we must do that as a reminder to all newcomers who might think that we all do have the same experiences. It is our way of saying to always be aware.

ASK THE DOCTOR

We received terrific explanations in a language we could understand from Glenn E. Peters, M.D., Director, Division of Otolaryngology Head and Neck Surgery, University of Alabama at Birmingham, AL.

He wrote to answer our early questions in a column we created for HeadLines. These answers helped to educate patients as HeadLines, were sent out by the American Cancer Society, and answered requests from patients, clubs, and SLPs throughout the country. Many people who did not have computers received the newsletter through snail mail thanks to ACS, and many made copies of it for their local clubs. Here are some of the questions and answers from the Ask the Doctor section.

Question: Why does my nose run all the time after my laryngectomy? Is it a cold or a sinus infection?

Answer: Your nose runs after a laryngectomy because you no longer breathe through your nose, but through your stoma. Because there is no longer any air flowing through your nose, the tissues lining the nasal cavities become engorged with blood and do what they are supposed to do—make mucus. This is a self-limited process and requires at least several weeks for the body to get adjusted before the condition improves. You should avoid taking any anti-histamine medications, particularly if you have had radiation, as this can make the dryness from the radiation even worse.

Question: Ever since my laryngectomy I seem to have trouble with constipation every once in a while and I really haven't changed my diet. Why is that?

Answer: In order to have a natural bowel movement, you need to strain a little. Normally straining is done by closing the vocal cords and increasing the pressure in your chest by exhaling against the closed vocal cords. The same thing happens when you strain to lift a heavy object. Without a larynx, you can't strain normally because your stoma will not allow you to restrict the outflow of air from your lungs. The solution then is to eat a diet which will provide a large amount of bulk to your stool, as in a diet high in fiber. Try your basic old healthy fruits and vegetable diet along with

grain products that don't have all the "good" refined out of them. You also want to stay very well hydrated with plenty of water, juices, and liquids.

Question: How do I know if they got it all?

Answer: By far and away, the question that I am most frequently asked is "Did you get it all?" I thought I might just explain this concept and let everyone know that the term "get it all" really doesn't apply to cancer, i.e. malignancies. Let's start by reviewing just what a cancer is in the first place. A cancer is a lesion that has the capacity to act in a lethal fashion and ultimately result in the death of the patient. Cancers come about when a group of cells, for whatever reason, loses their normal control mechanisms and begin to grow out of control. As a result of this growth and loss of regulation, some groups of these cells take on new genetic characteristics and become further programmed to carry out certain specialized functions. One of the most important new functions is the ability to invade the surrounding lymphatics and blood vessels, ultimately spreading to other parts of the body. Therefore, cancers are programmed to spread.

The ability of a cancer to metastasize or spread to other organs can occur at any time during a lesion's development and growth. We usually see this happen with larger tumors, but even the smallest and earliest cancers possess this genetically programmed ability to metastasize.

Surgery and radiation therapy are designed to take care of the tumor that exists locally in the head and

neck area. Unfortunately, at this time, there does not exist any form of therapy that can address cells that might get out and set up shop at other sites. The best we can hope for is early detection of any new sites of possible spread. That is why a program of close careful follow up and surveillance is so important.

So, in summary, we hope to eradicate tumors in the head and neck area with surgery and radiation. Most times we can get everything that we can see and feel. But does that mean that we "got it all?" Most of the time, it does indeed mean just that—but remember that we are dealing with a disease that by its very nature is designed to spread. So adopt a healthy life style and keep those follow up appointments.

Question: Is that why I have to see you so often, even though you told me you "got it all?"

Remember, the term "got it all" doesn't apply in surgical treatment, or any other form of treatment for that matter, when you're talking about cancer. Cancer is a diverse population of cells some of which are programmed to spread throughout the body. This can occur when a tumor is just barely or clinically detectable, or when the tumor is massive. It just depends on the genetic makeup of any given tumor. By the way, not all tumors necessarily have these groups of cells. Therefore, even though a cancer can be completely removed from the head and neck area, that does not mean that it may not have the capability to show up somewhere else in the future. To screen for this, we get yearly chest X-Rays,

blood work when indicated, and check for things like persistent bone or skeletal pain.

Next, we know that whenever someone develops a cancer in the head and neck there is between a ten to twenty percent chance that they will get another cancer in the region. This also includes the esophagus and the lung. We screen for these tumors by frequent physical examinations in the clinic. The head and neck is a wonderful area to work in for both the physician and the patient in that eighty percent of the area can be examined directly in the clinic without having to rely on expensive X-rays, CT scans, MRIs, and the like. Also, the general rule is that if your tumor is going to recur or a new one develop, eighty to ninety percent of these will do so within the first two years. That is why we see you more often during that time.

So, besides being a pleasure to see you and keep up with your goings-on, we are really trying our best to catch a problem in its very earliest stages; that is, when we have the absolute best chance to take care of it.

Question: We have many questions about excessive mucus. Will you tell us about that?

Answer: Coughing and phlegm are what I would like to address. Are you taking steps to make sure that the air that you inhale is properly humidified? Is your stoma bare or covered?

The excessive phlegm production is a natural response by your lungs when they are exposed to dry, unfiltered air. It's their way of protecting themselves. Irrigating your stoma with saline or clean tap

water every few hours will help. Two or three ccs at a time is all that is needed. Beware—you will cough like hell, but it won't drown you or anything like that.

Another thing you can do is to take advantage of the humidity that is leaving your body every time you exhale. Wear something around your lower neck like a woven stoma bib or a loose fitting kerchief; these things will trap some of your body's own expired moisture. Also, keeping your lower respiratory tract properly humidified will lessen your risks for viral infections (colds) and pneumonias.

Question: A reader from New Zealand wants to know about pain in her shoulders and neck area after laryngectomy.

Answer: A neck dissection of some sort to remove the lymph nodes from the right side of your neck can leave you with a lingering pain or numbness. In doing this operation, it is necessary to cut the nerves responsible for feeling in that side of your neck. The area of numbness likely extends from your ear down onto your neck, then onto the upper chest and the top of your shoulder. Unfortunately, the numbness is permanent to a large degree. The actual area involved may decrease in size as sensory nerves grow into the numb area from surrounding areas.

The weakness that you have noticed in your right shoulder is also from sacrificing another nerve in the neck, the spinal accessory nerve, which supplies the trapezius muscle on your back. The trapezius muscle helps you raise your shoulder when you raise

your arm. You have probably noticed that you have difficulty working above your head with your right arm. This is because you have difficulty raising your shoulder. The pain in your right shoulder is from stiffening in the capsule of your shoulder joint and also from some slight downward displacement of the shoulder from loss of the trapezius. The only real remedy for this is a vigorous program of exercise that is designed to strengthen the other muscles that help the trapezius to raise the shoulder.

The tightness and stiffness in your neck is indeed scarring in the soft tissues. Several factors have contributed to the development of this problem:

1. Radiation therapy causes fibrosis in the tissues under the skin, the amount of which can vary from patient to patient.

2. Surgery also can cause scarring.

3. A fistula and its repair can be a contributing factor. Each of these things can lead to the problem, but when they occur together, the problem is made much worse. Use stretching exercises and massage to loosen the scarred tissue. This is going to be a slow process, like six months to a year, but it should loosen up some if you work on it.

Question: When you perform a laryngectomy and cut the nerve that affects the trapezius, what problems can that cause for us later?

Answer: The nerve that you are talking about is the "spinal accessory" nerve and it makes the trapezius muscle work. The trapezius muscle allows you to raise

your shoulder, and thus your arm, over your head. Injury (or removal) of the spinal accessory nerve results in what we call the “shoulder syndrome” and it is characterized by pain and stiffness in the shoulder and the inability to easily raise your arm above your head.

The spinal accessory nerve is not cut as a routine part of a standard laryngectomy. It is taken, however, as part of a radical neck dissection to remove lymph nodes that are involved with metastatic cancer. Most surgeons will do what is known as a modified neck dissection wherein they try to save the spinal accessory nerve to avoid the shoulder syndrome, but stretching the nerve to remove the lymph nodes around it can make it function poorly none the less. These days, more nerves are saved than sacrificed.

The best treatment for the shoulder syndrome is exercise. Without use, the shoulder will become stiff and ache. The longer you wait to begin exercising, the stiffer and more sore the shoulder will become. This starts a vicious cycle of ever increasing pain and stiffness. So exercise the shoulder and strengthen other muscles to compensate for the loss of the trapezius. A perfect example of the type of exercise would be to imagine you were using a paint roller to paint a wall. Other folks like to use a pulley or a towel thrown over a door. The goal is to get that arm up above your head. A consultation with a physical therapist may also be beneficial.

Question: I'm being treated with radiation in an effort to save my voice but I am having trouble with swallowing and dry mouth. How long will this last, and what can we do to get through it?

Answer: It looks like you want some help getting through radiation therapy. We recommend some of the most basic things—diet modification, Ensure and similar products, blades (as we call the blender), fresh fruit, and the like. You're on the right track. Just like surgery, radiation causes a wound that requires adequate nutrition to heal properly; remember that even though radiation does not kill cancer by heating the cells, the side effects of the therapy are identical to a burn. Burns are some of the most physiologically demanding wounds and can affect metabolism in the most profound ways. And since these wounds are actually bigger and cover more surface area than a surgical incision, their nutritional and metabolic demands can be profound.

I hope that those of you who are smokers got the message that the reason you are in this predicament is very likely due to your tobacco consumption. Therefore, once and for all, use the problems that you are having with radiation to QUIT SMOKING. Use the analogy of burning leaves in the fall. Remember that wonderful smell as the smoke billowed off of that pile of burning leaves? Then remember what happened when the wind shifted and the smoke got in your eyes? It burned, didn't it? And exactly what is a cigarette but a concentrated bunch of burning leaves, right?

Next, let's talk about all that thick, ropy mucus that is building up in your mouth and your throat. At UAB, we are big believers in the powers of club soda. During our training as interns and residents we used sodium bicarbonate to clean out endotracheal tubes for patients in our intensive care units. That stuff was great at cutting

the thick, tenacious mucus that would build up in the tubes. Club soda, or carbonated water, has the same properties. When used as a mouthwash and a gargle it does a great job in cutting through the goo. You can also use it as a beverage for meal times as it seems to have superior wetting properties when compared to water alone. Buy the small 12 ounce bottles and keep them chilled. It won't work if it loses the fizz. Try it, you'll like it (hopefully).

Lastly, let's talk some serious nutritional delivery for a moment. Let's face it, radiation is no walk in the roses, although in the correct setting it can do just as good as surgery for treating cancer in the head and neck. All of the acute or short term side effects of radiation add up to make eating and drinking less than a pleasurable experience. Actually, food becomes more like medicine than anything else.

But remember, nutrition is the key to not only to a speedy recovery, but it also plays a large role in your ability to ultimately kick your cancer because you are keeping your immune system intact and healthy as well. The bottom line is this: if things get too bad and your weight starts to fall off rapidly, then you really might want to consider some sort of feeding tube to help you through the short term. At UAB we rely almost exclusively on the PEG or Percutaneous Endoscopic Gastrostomy to help our patients. In fact, we often put this in before radiation even begins, just so we know that we can keep a patient's nutrition up from the get go. We think that it really makes a difference. So if you really are getting in trouble, get a tube.

You should expect the recovery from radiation to take anywhere from three to twelve months, depending on where exactly you received your radiation. Folks who had their mouths radiated will take longer than those who received it only to their larynges. Hang in there. We know it is tough and we are pulling for you.

Question: Please tell me how long it takes to stop coughing up blood from my lungs and stoma? I am so tired of this, I just need to know.

Answer: Let's talk about your air conditioning system. Before your laryngectomy you were breathing through your mouth and more importantly through your nose. Your inspired air was being filtered and humidified by your upper respiratory tract. Inspired air was taken from the relative humidity of your ambient air and moisturized up to 100% by the time it reached the gas exchange units in your lungs, called alveoli. At the same time, particulate matter was removed by the mucus blanket, which coats the lining of the nose and throat.

After your laryngectomy, you were left without this normal filtration and humidifying system. Your lungs responded in a very normal and protective manner by producing an increased amount of mucus to filter and humidify the air that was coming in. Bloody sputum can result when you cough excessively to clear this increased amount of mucus. You also may be more susceptible to bronchitis (an infection and inflammation of the lining tissues of the tracheo-bronchial tree) because you are breathing unfiltered, dehumidified air. So, what to do?

1. Make sure you have had a recent chest X-Ray to rule out any significant lung pathology.

2. Make sure that your sputum is not discolored (in addition to bloody). Discolored is green or yellow. This may indicate an infection like bronchitis or pneumonia, which may require antibiotics.

3. Do everything possible to increase the amount of moisture in the air you inhale. Some tricks include wearing a stoma bib, but you can also wear a scarf or a turtle neck shirt or sweater. This allows you to conserve the moisture that is leaving your lungs in the area around your stoma. Another thing you can do is to irrigate your stoma with clean tap water or saline. Two to three ccs four times a day should help. Other tricks include wearing a soft stoma vent (see your M.D. for the proper size). A small plastic spray bottle filled with tap water can be used to create a mist to dampen your stoma bib. It becomes a portable humidifier. MOISTURE IS THE KEY. MUCUS RULES!

4. Lastly, be patient. Your lungs are going through some major changes. Ultimately, they will adapt to the new you. Things generally improve within three to four months after surgery.

As always, if problems persist, please see your M.D.

Question: There was a big discussion recently in our WebWhispers online group about using ointments inside or around the stoma. What do you recommend in the use of antibiotic or antibacterial ointments?

Answer: That’s a very interesting question. I think that if the stoma has “matured” or completely healed, then nothing is needed. If a raw area develops from something like using your speech prosthesis, then a short course of an antibacterial ointment is indicated until the area heals. I would not recommend a routine daily use of such products when nothing is wrong with the stoma.

I can think of three reasons that routine use should be discouraged. The first thing that comes to mind is that most antibiotic ointments have a petrolatum (i.e. petroleum) base. If a big “glop” of that stuff gets aspirated and finds its way into the lungs, then a lung abscess could result. The second has to do with the fact that the main function of having petrolatum in a medicine is that it makes a seal on the surface. That is why we use it on a fresh wound, 'cause it seals the bad guys out. The other thing it does though is to seal moisture and any surface bacteria IN as well. This will create a situation that is chronically "wet" and can actually damage normal skin. The last thing has to do with resistant bacteria. When bacteria are chronically exposed to an antibiotic, they mutate in such a fashion that they become immune or resistant to that drug. That is why antibiotics should always be used sparingly and only when truly indicated. The classic example of this is the horrible practice of prescribing antibiotics to treat a cold, which is generally caused by a virus.

So, when you have to use an antibacterial medication to treat an area of irritation around your stoma, use it sparingly and use a water soluble cream that won’t risk damaging the lungs.

Question: What on earth happened to my thyroid gland? Was my thyroid damaged during laryngectomy surgery?

Answer: First, the thyroid gland is shaped like a butterfly and lies in a position adjacent to the larynx and trachea. There are two lobes, one on each side of the larynx and trachea. These lateral lobes are connected by a narrow isthmus, which crosses the trachea just below the larynx.

In doing a laryngectomy, we try to save as much of the gland as possible. Usually, we can save both of the lateral lobes, which means you are left with essentially all of your thyroid tissue. However, sometimes it is necessary to resect half, or even all, of the thyroid in order to adequately remove the cancer. When we remove the larynx, we dissect the portion of the thyroid that we are going to save off of the larynx and trachea and leave it lying in the neck on either side of the esophagus. This means that your thyroid gland is actually in two halves, one on each side of the esophagus and slightly above your stoma.

The problem with thyroid function can come in several scenarios. The first one is obvious with the need to remove all of the thyroid tissue. You will be on thyroid replacement medication before you leave the hospital. (By the way, you will also be on calcium and vitamin D replacement before your discharge as well.) The other two scenarios are more subtle. The first involves leaving some thyroid tissue but compromising

the blood supply in doing the laryngectomy. What happens is the thyroid slowly gives up the ship and dies.

The last and probably the most common thing to happen is radiation therapy. The radiation causes the small blood vessels in the gland to slowly stop up so you end up with a small scarred gland with poor blood supply and inadequate function.

Does everyone who has radiation to the neck need to be on thyroid replacement medicine? The answer is no. If you are having the symptoms of becoming fatigued easily, low energy level, weight gain, etc., and if you have had radiation, then you should have your thyroid hormone levels checked with a simple blood test. Replacement medicine can then be given on the basis of those results.

Question: Can radiation cause dizziness or fainting spells (vasovagal syncope)?

Answer: Let's start by reviewing some anatomy. Then I will address the problem that some patients have when they turn their heads and get a little dizzy and lightheaded. On either side of your neck are the carotid arteries, which are the main suppliers of blood to the head and more specifically, the brain. This artery comes into the neck from the chest as a single large artery, the common carotid artery, then splits in the upper neck to become the external carotid artery, supplying blood to the face and head outside of the skull and the internal carotid artery supplying blood to the brain. Where this artery splits is called the carotid bulb and you can

usually feel it as a pulsating mass in the upper neck. The carotid artery and especially the carotid bulb are enervated by some specialized nerve fibers that are sensitive to the chemical content of the blood and also to the pressure of the blood inside of them.

Now, let's say you have had surgery on the neck or radiation to neck. Remember that either of these can cause some degree of scarring around this blood vessel resulting in some degree of "squeeze" on them. The nerves read this as an increase in the pressure inside of them and set in motion automatic measures to lower the blood pressure. These include a lowering of the heart rate and a dilatation of the blood vessels in the rest of the body. The net result of all of this is a relative lowering of the blood pressure to the brain and the sense of dizziness and being light headed. This whole thing can be made even worse if you have some degree of athersclerosis (cholesterol plaque) or if you are taking medicines for high blood pressure. Dehydration also may be a contributing factor.

If you have this problem, unfortunately there is not much that can be done to eliminate it. The most important thing is to simply be aware that the problem exists and not change positions rapidly, i.e. lying to sitting or sitting to standing. Take your time when you get up and don't immediately start walking. You might want to make sure you are well hydrated and that your blood pressure is under good control and your anti-hypertensive medicine is right for you. If the problem is severe enough that you almost black out or if it occurs frequently, please check with your doctor and make sure that you are not having transient ischemic attacks (mini

strokes) or something wrong with the heart itself causing it to be an inefficient pump.

Question: Everybody tells me to cover my stoma. Why do I need to do that and what do I use?

Answer: Stoma covers come in all sizes, shapes, colors. Some folks even use articles of clothing to cover their stomas. These include ascots, scarves, dickeys, turtle neck sweaters or shirts, etc. They all serve the same basic function and that is to keep the "bad" out and the "good" in.

Now let's talk about the bad first. Obviously, the stoma can present an exciting target for all manner of vermin such as gnats, flies, wasps, or bees. If your stoma is large enough, your children or your grandchildren at play may even pose a risk from any of a variety of projectiles. Most importantly, though, the air you breathe is dirty. Dust, dirt, and pollen offer the biggest challenges. This is especially true for those who work or play in dusty, dirty environments. So much for the "bad" we want to keep out!

Now you might just wonder what "good" the stoma cover keeps in. The answer is "moisture." Moisture is generated by your lungs and is lost with every breath unless something is done to retain it. And why is moisture so important? The most important reason is that the gas exchange in your lungs is most efficient when the humidity is high. A high moisture content also assists with the natural cleaning mechanisms in the lungs and helps cut down on what we all know as crusts. Folks who keep their stomas covered have much less problems

with crust formation; they cough less, have less mucus production, need to irrigate less, have fewer bouts of bronchitis, and so on.

Don't think of your stoma as your new nose. It doesn't work the same way. Keep it covered and you'll find you have much less difficulty with it.

Question: What is a neck dissection? My wife had a laryngectomy but I don't know whether she had the "dissection."

Answer: That's a big topic so I'll hit the highlights. Simply put, a neck dissection is an operation that is done to remove the lymph nodes in the neck. There are two fundamental types of neck dissections: one is done when we know there is cancer present in the lymph nodes ("therapeutic" neck dissection), and one is done when there is a high likelihood that microscopic disease may be present in the nodes, even though we can't feel them or they don't show up on scans ("elective" neck dissection).

Now, let's take this a little further. Therapeutic neck dissections vary depending on the amount of cancer that may be present in the nodes. Large, bulky nodes may require a "radical" neck dissection for complete removal. The radical neck dissection was first used in the first decade of the 20th century and has changed little since it was originally described. The radical neck dissection is the most comprehensive operation that can be done for cancer in the cervical nodes. It is a complete clean out of all node-bearing groups and also involves the removal of the internal jugular vein, the

sternocleidomastoid muscle, and the spinal accessory nerve that goes to the trapezius muscle. Obviously, this can result in a cosmetic deformity in the neck and more importantly, weakness in raising the shoulder and arm from sacrifice of the spinal accessory nerve.

Smaller nodes and elective neck dissections can be handled with a “functional or modified” neck dissection. This is a more targeted operation wherein the nodes that are either involved and/or at highest risk for involvement are removed. In doing the modified operation, we usually leave the jugular vein, the stercleidomastoid muscle, and the spinal accessory nerve. This results in less cosmetic deformity and less problems with your shoulder.

Neck dissections can be done either when the larynx is removed or later if nodal metastases appear. More and more, we are doing elective operations at the same time we operate on the larynx. We have found that this gives us important information about the status of the nodes (whether there is microscopic disease) and also whether we need to use radiation after surgery.

Question: Will I have to work harder to breathe after my surgery?

Pat came by the clinic for a visit recently. We got to shooting the breeze when Pat mentioned a fellow laryngectomee whom she thought might be hyperventilating and a thought popped into my head. That thought is this: A laryngectomee has a more efficient way to breathe! This has to do with something called "dead space."

When you have not had a laryngectomy, you can take a breath, air enters your nose and mouth, passes through your throat, through your trachea, and ultimately ends up in the lungs. In the lungs, small structures called alveoli put that air in contact with your blood, then gas exchange occurs. Your blood gives up carbon dioxide and gains oxygen in the alveoli. Therefore, any part of the air column from the nose to the alveoli that does not play a role in this gas exchange is considered "dead space." In this case, the dead space is the nose, mouth, throat, and trachea.

Now let's look at the laryngectomee. You have a stoma, which completely bypasses the nose, mouth, throat, and about one half of the normal length of the trachea. Hence, less dead space. Now, assuming that your lung volume is unchanged, this means that more of every breath you take goes toward gas exchange rather than filling dead space. This means more efficient breathing.

Well, that's my bit of trivia for the month. Mention this little known fact at your next family reunion and wow your family members with your knowledge of medical physiology.

Question: As a recent laryngectomee, what do I need to watch for in breathing, wheezing, coughing, sneezing, or runny nose, and when do I know if it means I should see the doctor?

Answer: People are often concerned that as a laryngectomee you are somehow different in how you deal with your respiratory tract. Well, the short and the

long of it is yes, you are different, but "different" is not necessarily bad. Removing your larynx and diverting your breathing through your stoma has removed the filtration and humidification provided by breathing through your nose, mouth, and throat. That means you're breathing in through your stoma air that is drier and has more particulate matter. All of this dirty, dry, air can make you susceptible to lower respiratory tract problems.

I've talked at considerable length about proper stoma hygiene to improve the filtration and humidification of your inspired air. Prevention is the absolute best form of staying in good shape. Humidify, irrigate, drink water, wear a stoma cover, spend some time carefully cleaning the area around and just inside your stoma and have clean hands when touching your stoma. Use moisture, good sense, and good hygiene.

Now for the good news about having a stoma: your airway is directly accessible for troubleshooting, diagnostic evaluation, and treatment. Normal nose breathers don't have that luxury. So what is it you need to look for?

1. A cough which is productive of blood may indicate anything from bronchitis to pneumonia to lung cancer. This needs to be looked into. Sure, you may have a little blood streaking in your sputum, particularly if you slip up on your humidification, but if this persists, don't hesitate to check in with your nearest health care professional.

2. A cough which produces discolored mucus usually indicates an infection of some sort. This is the

second big issue as it may indicate the need for a chest x-ray to look for pneumonia. It also may indicate the need for some antibiotics.

3. More crusts in the stoma, which means you should add more humidity.

4. Increased difficulty with breathing, particularly if it comes on suddenly, usually is caused by a crust lodged in the trachea. This calls for some tracheal first aid such as irrigating the stoma more frequently until the crust loosens up and becomes dislodged with coughing. If you are unsuccessful and are still having difficulty, GET SOME HELP!

5. Wheezing which is new in onset and noisy breathing are also usually caused by a crust narrowing the airway. You know what to do here.

6. Lastly, there is such a thing as having no problems and doing just fine. So what's wrong that? Did you get your chest x-ray this year? Remember that your laryngeal cancer puts you in a higher risk group for lung cancer, which can often get to a very advanced stage without the slightest hint of a symptom. Don't sit back and think everything is fine, and not follow up with your check-ups. The bottom line is you need an x-ray once a year.

Now for my disclaimer: Many of these breathing problems can mimic more serious health problems

having to do with the lungs or the heart. As always, when in doubt check it out with your doctor.

Question: I hear people talking about a fistula. Exactly what is a fistula, why do some people get one, and what can be done to help it to heal?

Answer: All right, let's talk about fistulae. By the strictest definition, a "fistula" is a connection between two epithelial surfaces. Epithelium is the lining of an organ or the covering of a body part such as the skin. The organs of most concern in the head and neck are the mouth, the throat, and the esophagus. Therefore, a fistula in our area represents a connection between the mouth, throat, or esophagus, and the skin of the neck.

What's the problem with a fistula? The most obvious problem is the leakage of saliva and anything else you swallow through the fistula onto the neck. The ramifications of this are obvious on social, convenience, and nutritional levels. Nobody wants to go around draining onto your neck all the time. Also, if the fistula is near your stoma, some of this stuff can go down into the lungs and possibly lead to pneumonia or a lung abscess. All of this leads up to the fact that we try to do everything we can to avoid a fistula.

What are the main causes of a fistula? At the time of surgery we try our best to close the inside of the throat and esophagus to avoid a leak. We use antibiotics during and shortly after your surgery to cut down on the chance of infection. The main thing that leads to a fistula is poor wound healing. Things such as too much tension on the wound, a wound infection after surgery, poor nutrition,

continued use of alcohol and tobacco, and prior radiation are the usual things that lead to problems with wound healing and the formation of a fistula.

So if a fistula develops, what can we do about it? The first thing we as surgeons do is to encourage it to drain into an area that will minimize the chances of infection in the rest of the neck and keep the drainage out of the stoma. Given enough time, most fistulae will heal on their own without additional surgery. Of course, there's the hassle factor of dealing with external drainage and needing to use an alternative method of feeding such as a PEG during the healing phase. Surgical closure is reserved for those fistulae which do not close on their own, and those that pose some danger, particularly to the stoma and the lungs.

What are the long term side effects of a fistula? The most commonly encountered problem is a stricture or narrowing in the upper esophagus, which may affect the ease of swallowing. Most patients who develop a fistula do not experience any long term problems.

AUTHOR'S NOTE: Some professionals refer to the TEP as a fistula, which is a technically correct term that's confusing to the layman, since most of us consider a fistula to be bad and a TEP (tracheoesophageal puncture) to be good. So in HeadLines, we will refer to the TEP as a puncture or as a planned fistula.

Question: What makes speech with a TEP?

Answer: There are differences in sound produced by different users of the TEP. You have probably noticed

in the Support Group meeting that some folks sound great and others seem to struggle. So why is that?

Let's start this discussion with the real way that a larynx helps "talk." To put in the simplest terms, all a larynx does is make the air coming out of our lungs vibrate. That's it—just vibrate. Speech does not come from the larynx, a vibrating air column does. As speech occurs, this vibrating air column is made into words by our throats, mouths, tongues, lips, teeth, and so on. A case in point is your Servox, which is also called an artificial larynx, and provides vibration only.

Now that we have this necessary background information, let's get on to your question. Remember that a TEP replaces the larynx by supplying another source of vibrating air. This time what vibrates is the lining of your throat in the lower part of your neck, just above your stoma. The differences in speech quality largely center around the differences in this part of the throat and upper esophagus. These differences include the following:

1. What was the primary closure method used to close the throat after the larynx was removed: vertical or "T" type of closure?

2. Was a flap of tissue transferred from another part of the body used in your reconstruction: jejunum, stomach "pull-up," chest muscle, or forearm flap?

3. Did you have radiation as a part of your cancer treatment?

4. Did you have an infection or a fistula after surgery?

5. Did you develop spasms in the muscles of your throat after surgery?

6. Do you have less than effective lung power?

7. Was it necessary to remove a part of your tongue with your larynx?

As you can see, there is a list of factors that play a role in the development of speech with a TEP. The bottom line is that each patient should be evaluated on an individual basis for this device. While the TEP is probably the state of the art at the present time, it might not be best for every patient. To find out more about your own prospects, ask your doctor.

ARTICLES

The following articles were written by other laryngectomees or professionals who know the basics that everyone should read. They will give you an understanding that will help you know your body again. We've had contributions from these people over the years, and they're great resources, especially for newcomers.

Voice Is Not All We Lost

Pat Wertz Sanders

The most obvious result of the surgery is being left without a natural voice. It is the part that is noticed and remembered by others, that we are truly voiceless. And yet, as we learn to speak using other methods, we slowly overcome that part. It's true, we don't sound exactly the same, but vocal communication is established and with a number of adjustments we start to take that part of our lives for granted again.

I saw this in myself and now I watch others making this same journey. It is particularly obvious at our support group meetings. We meet once a month and we see a person who is struggling with learning the Servox one month starting to be understood fairly well the next. By the third month, most of what is being said is understood; six months down the road, the EL is flipped up to the neck, and the patient is automatically phrasing sentences so they are heard distinctly. Speaking this way has become a controllable part of each new life. Because we now communicate in an <u>almost</u> normal fashion and because our friends and families have become accustomed to our new voices, they sometimes forget that talking is not all there is to adjust to in this post-laryngectomy world.

The parts that are not so well remembered by others are the parts we work constantly to control. We taste, smell, and breathe differently, and our noses either drip or dry up. Mucus production goes wild for a while. It does get better gradually, but even then we have good

and not so good days. We may be talking so clearly with the TEP that we sound much as we used to, but then start to sneeze or cough and all of a sudden we can hardly talk with the quantity of mucus being produced. New laryngectomees ask about this all the time because it is constant right after surgery.

The answer is that the mucus will lessen and the intervals between coughing spells will be longer. Sometimes we will have sudden coughing spells when at a movie, when we enter a shop, or stop to get gas. Who knows what triggers them? It could be something in the air like fumes, perfume, or smoke, or just the change of air quality from dry to moist or hot to cold. So, what do we do? In a movie or a meeting, sit on the aisle so you can step out if you need to. Carry cough drops or mints and if you can, to stop it before it starts. You will learn to do the appropriate thing to take care of stopping the cough and cleaning up the results.

Simple things can become complicated. I went to the dentist because of a broken tooth that required a crown. My dentist has a chair that lays me almost flat, so what happens to anything that gets in my throat? They used to sit me up, hand me a cup of water and I would gargle, rinse, and spit. That's not exactly something we're able to do well, so I worried about getting some sediment in my throat from the tooth they were preparing. I knew it would make me cough and, once started, I would have a hard time stopping. My solution was to warn them of my limits, that I could not cough up anything they dropped into my throat. Their response was for the assistant to be extremely solicitous is using the vacuum and the dentist moved back several times to

let her be sure she got it all. With teamwork, another problem was solved.

I used to cook by smelling the aroma of spices. I knew biscuits were ready by how they smelled. Milk, slightly soured, was used for cooking, not drinking. If there was the faintest odd smell to meats, I knew it. This ability is gone and I worried a little that if I ate food that had gone bad, I might not know it until I got sick later.

My taste buds used to be so very sensitive that I could figure out what herb mixture had been used for seasoning in various dishes. Now, I go by looks, timing, and my memory.

Every day, we are confronted by the differences in our lives and we learn to deal with each little problem or project that arises. If we share with each other and are willing to learn, we can save a lot of discomfort. Our lives are full of learning experiences and if we don't learn from each one, we're doomed to having the same problems over and over. We will be learning for the rest of our lives how to live a different way than we used to. It's slow going, but life is worth every minute of the time spent adjusting.

Acceptance

Pat Wertz Sanders,
written for Apr 1997 issue of HeadLines

A new e-mail laryngectomee friend asked, “How is your acceptance of what you've been through. Does it still occupy 100% of your thoughts?”

NO WAY! Maybe it takes up ten percent of my thoughts since I’m still dealing with problems and learning new ways of handling them. I’ve added another chore or two to the normal morning and bedtime routines, and have learned to check my voice on the way to answer the telephone to be sure it’s clear. The day-to-day maintenance care has become part of the business of living and it's time to let go of the illness and accept these things as part of my new lifestyle.

Acceptance is the end part of the process of suffering any loss, and the removal of a voice certainly qualifies as a major loss. Getting to acceptance requires going through disbelief, anger, and depression. We can linger in each of these stages for varying lengths of time, sometimes with anger and depression see-sawing back and forth. Everyone is different in the way they handle their losses and some tend more toward depression than others. We all eventually get to the level of accepting the loss and going on from there. If we are flexible enough to accept a new set of rules based on reality, we come through in great shape.

Once the pain and suffering are gone, those of us who are optimistic by nature can find a few good things to be pleased about. I remember the weeks of miserable

sinus infections I had twice a year, every year. They have disappeared since my surgery, and now my friends don't complain about theirs since they know my standard answer is, "I have a perfect cure for that!"

I don't think it's unique to me, but among laryngectomees I feel normal. I do not consider myself to be "handicapped." I'm not shying away from the idea, it just doesn't occur to me. I have found a word that expresses what I do feel: inconvenienced. Believe me, I can deal with that!

It Isn’t All In Your Head, But Some Of It Is!

Wilburn H Rivenbark, Ph.D.

A professor of psychology who had experience with cancer was willing to write for us about his experiences and to give advice that we can take away with us. Wilburn H. (Rick) Rivenbark, PhD, is a retired clinical psychologist and a former professor of psychology at the University of Alabama. He has had two previous bouts with larynx cancer, the first occurred thirty years ago and was treated with radiation, and the second round was twenty years ago and required a partial laryngectomy. His naso-pharyngeal cancer was discovered this year at his annual checkup.

In writing this article on how to deal with the effects of cancer from a psychological standpoint, I decided, after some thought, to use my own case as an example. While each person's experience of cancer is unique in some ways, I believe there are some general principles everyone can use. I hope these tips will be helpful for you, not only during your recovery, but long after as well.

I had felt the emotional effects of dealing with cancer long before I ever got it myself. An aunt, a childhood friend, and a favorite boss had all died from it, and a couple of my friends had had surgery and treatment for it. I had even had an occurrence of cancer in polyps on my vocal cords, which I did not find out about until the surgery was done. As painful as these events were, they were nothing compared to the emotions I experienced when, nine years later, I was told

I had cancer in one of my vocal cords and that I would probably have to have a total laryngectomy. Later, after an evaluation by a second doctor, I was told I might get by with a partial laryngectomy.

What first went through my mind was that it was the worst possible place for me to have cancer. I made my living teaching, lecturing, and doing psychotherapy. I could function pretty well with an arm, a leg, or even a lung missing, but without a good voice I was done for. Even some of my favorite leisure time activities, acting in community theater and singing, were lost. Furthermore, neither my medical nor my disability insurance would cover me because I had had the previous cancer. I experienced spells of fear, anger, depression, and a hopeless/helpless paralysis of mind, emotions as severe as any I had treated in my practice.

Fortunately, after going through a few days of this, I got my thinking back to a more rational level. I began to use some of the techniques I had been teaching to my clients and patients. A basic part of my therapy technique is to help people see that their thoughts affect their feelings and actions, and that by changing the way they think about something they can significantly change the outcomes. As Shakespeare wrote, "There is nothing either good or bad, but thinking makes it so." I had fallen into the trap of irrational thinking - catastrophizing the bad and ignoring the possibilities for making things better. I had to remind myself that the mind has great power to promote healing and well-being, if we will only use it in the proper way.

Don't catastrophize. An example of this is to imagine the worst case scenario without evaluating

the actual probabilities of it happening. In my case, I was ignoring the probability that I would not die from my cancer, which would be the real worst case. I had not been evaluated by a cancer surgery specialist, so I did not know what my options were.

Realistically evaluate the most likely consequences of your situation. A total laryngectomy would indeed mean a great change in the way I practiced my career. However, I would likely come out of the illness with my mind as well as most of my body intact and healthy.

Examine and evaluate your goals. What do you really value? What do you really "need," as opposed to "want," to make your quality of life acceptable? I "wanted" things to stay as they were, but what I "needed" was a way to make a living using as many of my current skills as possible.

Utilize resources for information, help, and support. There are usually resources available we have not thought about or used before because we didn't need them. Wonderful friends and family members searched out some of these for me. Vocational Rehab agreed to help with my medical expenses. I was referred to a woman who had gone through total laryngectomy and she was able to help me realistically evaluate my post-surgery possibilities. The American Cancer Society told me of support groups such as TOUCH and Lost Chord. Nowadays, you can get online with a computer and find cancer support forums with people all over the world to communicate with.

Develop alternative ways of reaching your goals. What do you need to do to get back on track towards your goals? I needed some ways to "do

psychology" without a lot of oral communication. Through the Independent Living Center, I found out I could learn sign language, and that there was a great need for psychologists who could work with the deaf. As it turned out I was able to get by with a partial laryngectomy and did not need to utilize sign language, but I did learn some and have found it useful. I also discussed doing some articles and even a book with my colleague.

Keep your thoughts focused on healing and success. Research is showing that positive thoughts and attitudes, especially when combined with frequent positive visualization of goals, can significantly speed healing and improve chances of success. I used my skills in positive visualization and self-hypnosis to both recover from the surgery and to restore a passable level of oral speech, although it took nearly a year. You can learn these skills from a variety of sources, ranging from books to classes to therapists trained in the technique.

Learn to enjoy the things you still have and can still do. This may sound trite, like the homily of making lemonade if life hands you a lemon, but it is still true. I greatly miss doing community theater acting and singing, but I could still help with lighting, sound, set construction, etc. Sometimes you need to develop new hobbies or interests, and you may find things you never would have enjoyed otherwise.

Be innovative; be flexible. "The way I've always done it" is not the only way, or even the most satisfying.

Prevention Of Radiation-Induced Dry Mouth

Rick Rivenbark

Recently I had to undergo radiation treatment for a cancer discovered in my naso-pharynx (the area where the nasal passages join the throat). Even though I was to receive IMRT, a highly focused type of radiation designed to minimize radiation exposure to all areas except the tumor itself, I was still due to get a pretty heavy dose to my salivary glands. It was explained to me that this could kill all or most of the saliva-producing cells and result in a permanent dry mouth. In order to prevent this as much as possible, my physician elected to irradiate one side of my face less intensely in order to try and retain some salivary function there. To provide additional protection to the glands, she administered amifostine (am-i- fos'-teen) prior to each radiation treatment.

Amifostine is in a class of drugs known as chemoprotectants; it protects the kidneys against the harmful effects of the cancer-fighting drug cisplatin in patients with ovarian cancer or lung cancer, and reduces the severe dry mouth caused by radiation treatment after surgery for head and neck cancer. In my case, it was injected thirty minutes before each treatment.

The most common side effect of amifostine is a decrease in blood pressure, which may start while the drug is being given and lasts about six minutes. It can also cause nausea and an allergic type rash at the site of the injection, as well as other side effects. In order to minimize these, I was put into a recliner during the

injection and for the thirty minute wait afterwards. My blood pressure was also checked. I also took an antihistimine and an anti-nausea medication about forty-five minutes before going for my injection. I was very fortunate in that my blood pressure did not drop as a result of the amifostine. The preventive meds I took in advance kept me from having any side effects other than being drowsy for most of the day. I am very sensitive to sedative effects, and both the antihistamine and anti-nausea drugs had sedating properties.

I am now three months post radiation, and still have very minimal saliva production. My physician says that there is still a good possibility of it getting better and has also put me on a medication called pilocarpine (pye-loe-kar'-peen), brand name Salagen. This is a drug that stimulates the cells of the salivary glands, causing them to grow larger. In this way, they can help increase saliva flow. This drug is also used to treat dry eyes in certain cases. Salagen is slow acting and the drug information sheet cautions that it may take three months to work. I have been on it for about six weeks so far.

I am optimistic that all the steps taken to keep my salivary glands working, at least partially, will eventually pay off. In the meantime, I keep a bottle of water handy at all times and sleep with a room humidifier going.

Radiation - A Treatment That Leaves Traces

Hank Luniewski

Most laryngectomees have had radiation. It has been the first line of defense against throat cancer for years and there are many people for whom it worked. It got rid of a cancer that has not come back. Many of our laryngectomees ended up buying time with radiation and lived with the larynx and voice intact. Radiation is known for leaving patients with dry mouth, unhealthy tissue, and teeth that may have been damaged.

Hank Luniewski, one of our members who has been through several rounds of radiation in the same areas, has offered his experience:

I first had throat cancer in 2006 at the age of 57. It was stage three squamous cell carcinoma of the base of the tongue. I had 35 radiation treatments, losing 75 pounds in the process. It appeared to have fixed the problem.

Four years later, the cancer came back. I had a laryngectomy and a glossectomy (tongue surgery) with reconstruction of my esophagus and tongue from my left thigh muscle. I also had the lymph nodes in my neck removed. A PEG tube was installed for nutrition during recovery.

Eight months later, the cancer was back again. In September 2010, I had a radical neck dissection with reconstruction using the right pectoral muscle from my chest in an eleven-hour surgery. A PEG tube was reinstalled for nutrition during recovery. This operation was followed by a round of chemo and another 33

radiation treatments, for a total of 68 radiation treatments.

There could have been problems with going through a second round of radiation. as I was adding 33 treatments on top of the 35 that I had received. already. I actually found the second time around to be easier, maybe because I knew what to expect and was prepared for it. Getting the mask put on and fastened to the table felt like routine operations. I think it was a piece of cake the second time because the fear and uncertainty were gone. All I wanted to do was kick the cancer's butt and get on with life. I'm several years out from my last treatments, and my scans have all been good.

According to my learned SLP, Dr. Carla Gress, there are two main problems with radiation and dental issues. The first problem is a dry mouth caused by the effect of radiation on the salivary glands. A dry mouth allows air to get to the teeth. Air on the teeth can promote bacterial growth. And we all know that bacteria on the teeth can lead to cavities. The second problem is the effect of radiation on the blood vessels to the teeth.

Radiation actually scars our blood vessels. The scar tissue causes our blood vessels to shrink, which may restrict some of the blood flow to the teeth. Too much blood restriction can lead to our teeth possibly dying and breaking off. Please keep in mind that these are possible side effects of radiation on your teeth. Some of us experience them, and some of us do not.

As a side note, this vessel shrinkage can affect the neck arteries as well. Many of us have had ultrasounds to determine if we have any arterial problems. In my case, for example, my right neck artery is flowing in the 39 to

50 percent range and is considered tortuous, which means the blood is not flowing in a straight line. When I turn my head to the right for more than a second, I can pass out. The doctor gave me the sage advice, "Don't do that," then sent me a bill.

The best way to stop this dental radiation problem is frequent brushing after every meal and at bedtime, and treating teeth with a fluoride solution. I use Prevident 5000, which I must get from my dentist by prescription. Another treatment you may consider is a mouthwash containing a small peroxide solution.

One thing a new laryngectomee may not understand is that with our new limited ability to swallow we don't realize that food can lay in the mouth not swallowed. I made this mistake. I further made the mistake of not brushing at bedtime when I was really sick and tired from the radiation and chemo treatments. I thought that I would brush in the morning and that would be okay. It wasn't.

Life is great now. I am unable to speak due to the extensive surgeries but get by just fine with my white board, texting, cell phone notes, and apps. Most laryngectomees are able to speak in some manner. I am in the minority that cannot speak. I am enjoying doing everything I did before except speaking and swimming. I keep up my home and property, play golf regularly, take my wife, children, and grandchildren to the beach every year, and take driving trips with my lovely wife.

I plan on volunteering at UVA for many years to come, helping others transition to their new normal.

Some Tep Problems: Advice from the Doctor

Glenn E. Peters, M.D., F.A.C.S.

Your TEP is in a real dynamic piece of anatomy. The site constantly moves with swallowing and breathing. The area is manipulated with your finger or thumb when you use your prosthesis. In addition, there is the issue of constant bacterial and fungal soilage from the organisms that live normally in your saliva and sputum all of the time. So with all this going on, it is no small wonder that things happen to the fistula (puncture) that we made which can affect your ability to successfully use it.

The most common problem that we see with the TEP is failure to properly seat the prosthesis in place. The inner flange does not engage the inside of the esophagus so the tissue in the tract closes over the opening on the esophageal side, even though it looks like everything is fine on the stoma side. If caught early enough we can often re-establish the opening in the clinic. Otherwise, we have go back to the operating room for a re-puncture. So always check your ability to make a voice a few times after changing your prosthesis. If this changes several hours later you are likely dealing with a mal-positioned prosthesis. Try to reposition it yourself and even use your dilator if you are comfortable with it. If you are still having trouble, contact your MD or speech pathologist for help right away.

Because there is constant motion and intermittent manipulation, the position and angle of the tract can change over time. We have seen fistulas that actually

migrate up and out of the stoma! The tract can change its angle and many times ends up pointing upwards towards your mouth. Changes in the angle usually lead to leakage through the prosthesis and the fistula. Although it may be possible to "re-train" the angle of the fistula by using a red rubber catheter taped on the top side of your stoma, these problems usually require a re-puncture to achieve optimal results.

The last issue I would like to address is the problem of granulation tissue developing around the fistula. This almost always happens on the tracheal side and is caused by manipulation, irritation, and bacterial contamination. Acid reflux and the bacteria associated with saliva and sputum also enhance granulation formation. It can hamper your ability to accurately place and position your prosthesis and can be a source of bothersome bleeding. This problem is generally handled with local excision in the office using a small hand held laser or a cautery.

The problem in the esophagus is a little different matter. For esophageal problems like granulation or erosion and for fistulas that migrate out of the stoma we often have to completely disregard the current fistula, let it close and come back in a month or so for a re-puncture. This lets everything heal and creates a more controlled situation for a better placement. Usually the fistula will close once the prosthesis is removed, but it may be necessary to close the tract with an outpatient procedure before the repeat puncture can be done. After the repuncture, we basically start over with resizing as the tract matures.

Checking your TEP should be a routine part of your follow up cancer surveillance each time you go to your head and neck surgeon. You should also periodically check it for problems as things that are caught early generally have simple solutions and do not require trips back to the OR for repeat puncture.

A Visit To The ER

Scotty Chandler

Thanks to all of you for your thoughts and prayers during my recent hospital visit. Any hospital emergency visit is scary, at best. In my case, the heart attack or myocardial infarction (I had two of them, and three operations in two days), was caused by a clogged artery and a blockage. My understanding is this causes damage to the heart muscle itself because it cannot get oxygen. This artery has to be opened immediately or else damage gets worse or death occurs.

There is a "clot buster" injection that immediately starts a super-thinning of the blood, which can lead to a profuse amount of bleeding from the stoma or lungs. In my case, I was already coughing slight blood specks, which is normal for me at this time of year. So when the shot came, so did the gushing blood from the stoma. It was up to me to cough the blood out or have someone who could suction it, and I'll bet not one ER worker in one hundred would know what to do even when trained properly. I more or less had to tell the excellent ER doctor, "You take care of the heart. I'll take care of the breathing and bleeding, and let you know if I need help."

The blood begins to gel much as mucus does as you breathe and air hits it. You can't blow it out, thus you need to irrigate to thin and cough it out. I had to make it clear when the blood started coming up that I had not taken medications for pain, or anything that might be mind or muscle altering. I could take care of the blood and be able to communicate with the eight or

so nurses by using my Servox. It was scary as hell, even in an ER that had a laryngectomee poster hanging up that I had posted there a year before.

During the time in the ER and during the bleeding for about a two and a half day period, the Servox was my best buddy. When the blood hits the air, it gels and starts to scab over the hole in the TEP prosthesis, closing off any means of communicating other than hand signals. Believe me, trying to write notes as an alternative speech when you're weak or scared is not too good. Waving your arms using monkey motions is often misread. To those of you who think an electrolarynx is unnecessary since you speak clearly with your TEP or using ES, you might think again.

I am three and a half years post-op and speak very well with either a TEP or EL, and this was the first real emergency where I had to use alternative speech. The orange card from ACS and the emergency card from Lauder showing neck breather drawings and the placement of the TEP allowed me to explain "how" and "what" quick and clearly. The Servox helped me to tell them what I needed for my part of the job. This prevented me from drowning in my own blood or from having other serious problems if the prosthesis was removed.

I've heard people say it was too much trouble to keep up with their Servox. Trouble to keep up with my buddy? I don't think so!

Swallowing Difficulty After Partial and Total Laryngectomy

William Carroll M.D.,
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Some degree of difficulty swallowing (dysphagia) is common after most types of laryngectomy, whether total or partial. In most cases, the swallowing problems are not severe and tend to improve over time. The causes of swallowing difficulty differ depending on whether the laryngectomy has been partial (hemi-laryngectomy, or supraglottic laryngectomy) or total.

Let's discuss the "partial" laryngectomy situation first. As you know, the production of sound or voice is not the most basic function of the larynx. The most basic function is to separate the food and the air, which are both taken in through the mouth. The larynx acts as a gate or door. It closes by reflex action when a swallow occurs. It opens when air is inhaled, and closes when food or liquid is swallowed. It keeps air moving toward the lungs and food moving toward the esophagus. Part of the larynx is removed during surgery and part of the normal nerve supply is interrupted. The reflexes that direct the larynx to open and close are often disrupted. The main problem that develops is aspiration, or food going into the breathing passage (trachea) instead of the swallowing passage (esophagus). Aspiration may be minor and cause nothing more than a little cough with swallowing, or may be severe and cause pneumonia. Early after surgery, almost every patient has some degree of aspiration. Typically this situation

improves with swallowing therapy and oral intake can be resumed. Unfortunately, there are occasions when the protective reflexes can never be fully regained and oral intake remains unsafe due to the risk of aspiration. This is rare but can require long-term feeding tube dependence.

In contrast, aspiration almost never occurs after a "total" laryngectomy because the breathing and swallowing passages are surgically separated. To understand the swallowing changes that occur after total laryngectomy, a little anatomy review would be helpful. The back wall of the larynx actually makes up the front wall of the pharynx or upper esophagus. When the larynx is removed, part of the front wall of the pharynx/esophagus is removed also. When the remaining portion of the pharynx is closed with sutures, the circular opening becomes smaller. Imagine a string tied in a circle. Cut out a piece of the string and toss it out. Now tie the remaining two ends back together. The new circle will always be smaller than the original circle. Just how much smaller depends on how much string was removed. Those patients who start with tumors confined to the inside of the larynx usually have plenty of pharynx left to make a very adequate swallowing passage. Some, however, not only have their larynx removed, but also have part of their esophagus or pharynx removed as well. For these patients, the new “circle of string” can be quite tight. The extreme situation occurs when not only the larynx but also the entire pharynx or upper esophagus has to be removed. This is called a laryngo-pharngectomy. In these cases, the swallowing passage has to be completely reconstructed using small intestine,

stomach, or a tube-shaped skin flap most often taken from the forearm.

Total laryngectomy also disrupts the nerve and muscle fibers that normally contract to help food move down the esophagus. Occasionally patients will have spasms of the remaining muscle, which makes the opening into the esophagus very tight. Plenty of tissue is present to allow easy swallowing, but the muscles are in spasm (hyper-contracted) and won't allow food to pass. This situation can necessitate a surgical procedure called a myotomy (myo = muscle, tome = to cut) which divides the spastic muscle.

The other factors that can lead to difficult swallowing are radiation before or after surgery, or a wound infection or fistula occurring after surgery. Both make the tissues of the pharynx and esophagus more stiff and less stretchy when food is trying to pass. Both processes can actually narrow the caliber of the opening into the esophagus as well.

Many of the same factors that affect swallowing so dramatically after laryngectomy can also affect the ability to use a voice prosthesis (Blom-Singer valve) or esophageal speech.

That's a Hard Pill to Swallow

Introduction to difficulties in swallowing after laryngectomy

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I attended my first IAL Voice Institute Annual Meeting in 1998. It was wonderful to have the opportunity to learn from and socialize with laryngectomee participants. One of my most memorable learning experiences did not occur in the context of a lecture or one of the many hands on training sessions. It occurred at the annual meeting banquet. Before the food was served, the room was filled with typical mealtime sounds. After the food was served, the room became oddly quiet. I could still hear clanking plates, scraping silverware, and unmistakable laryngectomee coughs, but the chatter was nearly completely gone. It suddenly hit me, "Hey, it's difficult for laryngectomees to speak and eat at the same time."

It was really interesting to watch people communicate with facial expressions, gestures, points, head nods, and winks. Something else struck me as I looked around the room: quite a few laryngectomees were having difficulty chewing and swallowing. Most of the laryngectomees were slowly and methodically eating and drinking. Some laryngectomees were strategically pushing their food around on their plate and occasionally lifting a partially loaded fork or spoon to their mouths. A

few Voice Institute Annual Meeting attendees were curiously absent. I now realize they were behind closed doors sipping their dinner or dumping a can of Boost or Ensure down their tubes. As a speech pathologist, I understood the clinical implications of swallowing difficulty (malnutrition, dehydration, coughing/choking), but I was only now starting to have an appreciation of the social implications of having difficulty swallowing.

Dysphagia after total laryngectomy is a real and common problem which in all likelihood is underreported. Many laryngectomees have told me they were counseled their swallowing function "would not be impaired" after laryngectomy or that in fact their swallowing function "may actually improve because they will not be able to get choked." Many patients do not complain to their physicians about their swallowing issues. Those who do complain are often encouraged to just be "glad you're alive" or "happy that you can get down liquids or baby food."

The prevalence of dysphagia following total laryngectomy has been reported to range from 17% to 70% (Balfe et al., 1982; Maclean, Cotton, & Perry, 2008). Ackerstaff (1994), in his study of dysphagia in patients post laryngectomy, found the wide variability in reported prevalence is because different investigators have different definitions of "successful swallowing." Some investigators define the ability to eat a soft diet as "successful swallowing." Other investigators define "successful swallowing" as the ability to meet nutritional needs without a feeding tube, regardless of diet consistency. Akerstaff (1994) stated that while "such broad definitions of swallowing success may be adequate

when evaluating the outcomes of different surgical techniques, it fails to accurately reflect the number of patients post-surgery who are unable to resume their normal, premorbid swallowing function." He further noted the "literature underestimates the number of patients who may experience difficulties and associated distress related to altered swallowing function post-surgery." In one study, Ward (2002) reported, three years post-surgery, only 58% of the laryngectomees managed a normal diet. Moreover, the laryngectomees who were identified as having long-term swallowing problems or the inability to eat a normal diet identified themselves as having increased levels of disability, handicap, and distress. Even laryngectomees who did not have significant difficulty swallowing reported slight levels of handicap and distress resulting from taste changes and increased durations required to complete a normal meal.

Not being able to fully participate in or enjoy the social aspects of eating a meal or having a beverage with family or friends clearly has a negative impact on overall quality of life. Eating may nourish the body, but sharing a meal with family and friends nourishes the soul. Many of my laryngectomee patients and friends tell me they are frustrated and sometimes embarrassed about their inability or difficulty with eating and drinking in social situations. I know many laryngectomees who avoid social activities where eating or drinking are involved. For individuals with modest difficulties, sometimes making simple changes to the environment or educating family and friends may over time reduce feelings of frustration or embarrassment.

A few dining tips that could be of use to laryngectomees in choosing a place for dining out: select a quiet restaurant, if possible, and try to find a well-lighted area in the restaurant. It can be difficult to be heard or clearly understood in a noisy environment and it's often hard to see gestures, facial expressions, or head nods in dimly lighted rooms. Keep in mind that cocktail parties, buffets, and family style dining each present a different challenge. It's difficult to fill and balance a plate while simultaneously using a hand to occlude the stoma or operate an artificial larynx.

If it's difficult for you to communicate and eat at the same time, you need help speaking up to order, you have problems swallowing, or you eat exceptionally slowly, then consider telling people in advance. It can be awkward if your dinner companions finish their meal before you have completed yours. Give others at the table permission to eat without you and suggest they continue through dessert. If food sometimes sticks in your throat, have an escape route in mind just in case you need to suddenly excuse yourself from the table. If coughing during mealtime is an issue, reassure your dinner companion that you can't get choked in the sense that they can, and even if you are coughing, your breathing is not obstructed. You will let them know if you need help.

It is so much easier to be served since buffets are great for choices of food but not for getting your food. It's so difficult for anyone to get a plateful of food, a drink, or a dessert, but it is especially difficult for a laryngectomee who might need a hand free to speak.

Don't deprive yourself of the good food and company that you can enjoy by eating out, and learn the little tips that can make it more pleasurable.

Be Aware

Pat Sanders

We should be educated about what is and has happened to us with cancer and, thanks to the Internet, that information is plentiful and easy to obtain. Actually, some new laryngectomees may be getting advice that is far beyond what they can use or need.

It reminds me of the five-year-old asking her mother where she came from and, after listening to a long, detailed explanation of how children are created and born, the little girl said, "Well, I just wondered because my friend Mary said she came from Alabama." Sometimes we get an overload of information.

I see this overload on the email lists, where we can read more in a month from the folks who have been there than we can in a year of research on our own. Be aware that all statements are not true for all people. I have seen messages written to ask a simple question and the answers get so far afield that the person who posted it has to go back to read the question because she forgot what was asked. And then there is the person who reads the answer and addresses that answer instead of the original question, and in three or four messages, we are so far off the original topic that no one can find what started the subject. This can get confusing enough for the old timer and be a total mess for the new lary.

Learn from other larys, but know that there are differences in us and in the way we need to take care of ourselves. If a diabetic should tell you that staying away from sugar and taking insulin will cure what ails you,

would you go ask your doctor for insulin, even if you're not diabetic? No, of course you don't do that. However, read carefully and remember that many of us first learned that we needed a blood test for thyroid problems after we read about it on the lists. Sometimes the doctors do not even think about there being such a need.

All doctors are not created equal in lary knowledge and information either. I have a wonderful doctor who listens to me and stops to check when I have a concern. Sometimes he tells me immediately that I am wrong because I would have certain other symptoms if my theory was true, but sometimes he makes a suggestion to try something for a period of time that will give us some different information and perhaps a diagnosis.

I remember when I had flashing lights and shining triangles slowly moving across my eyes; it was scary. I could not see well, and I didn't know what was causing it or how often I would have it. But I did know that bright lights made it worse and helped bring it on. My eye specialist told me my eyes were very dry. I learned to put drops in my eyes several time a day.

When this weird vision would happen, I would use the moisturizing drops and lie down in a darkened room for about twenty minutes with my eyes closed. When I opened them and moved slowly then looked around, I would be okay. The next episode might be the next day or weeks down the road.

I used every possible combination of words to describe what would happen to me as I searched the Internet for my symptoms. Finally, I saw some pictures and drawings of exactly what I had been seeing and I had a name to pursue: ophthalmic migraine, sometimes

called a silent migraine if you had it without the migraine pain. The more I read, the more sure I was. So when I went to my regular doctor for my next annual checkup, on my list of things to tell him was my self-diagnosis. He jumped to finish my thought when I started telling him. He had gone through a similar experience and couldn't figure out what was happening to him. He said he was a doctor and didn't put it together. He had gone to another doctor, a friend, who told him immediately that he was having ophthalmic migraines. As soon as he heard my description, he knew it was right.

I like my doctor and he respects me. Actually, he was the one who suggested last year that I write a book, and a few weeks later, I started putting this one together.

We must be aware that all information is not equal nor does it necessarily pertain to everyone. If someone writes a message about a piece of equipment or a new gadget, don’t assume that you have to have it to survive or that it will be a miracle for you. For instance, if you have difficulty coughing up mucus, a suction machine might help, and might even be a daily necessity. It might only be needed in an emergency. But unless you have special problems, before you become dependent on another machine, ask your doctor and try the simple way first. Get enough moisture in your body to thin your mucus. Drink enough water, irrigate, and use humidifiers. Sound too simple? For most people, it works.

Another handy-dandy machine is the speech amplifier, and I have had people ask me about it because they’ve been told it would make talking easier. It

actually only makes talking louder, so if you have a very soft voice and need to be loud enough to reach a group of people or have to talk over machinery noises, it is very effective. But it does not talk for you and it doesn't clear up your speech. If you run one word into another and are hard to understand, your speech will be just as hard to understand with an amplifier, but it will be louder and have a volume control. Practice enunciating clearly as best you can. That is where you start.

The key is to know which products and machines will help your problem (other than ones that are prescribed for you). Don't buy something just because someone else uses one. Don't buy something because it is on sale, either (unless you had planned to buy one anyway). Be aware that a vendor is not responsible for what you buy, since they don't know if you need it and they are in the business of furnishing what you order. Our vendors are not snake oil salesmen and most of them will tell you straight. Let's face it, we are a small community and word gets around if someone pushes a product that doesn't work or is useless. We've had those experiences and that is when BE AWARE becomes BEWARE. No vendors want to put themselves in that position.

Healing Touch

Shari Aizenman, a massage therapist from Personal Attention, wrote a series of articles for our newsletter on the benefits of touch and massage. Those articles, called “The Right Touch,” became the first chapter of the pamphlet that we put together with Leonard Librizzi.

As my friend and massage therapist, Shari Aizenman was from Atlanta but had family in my town. She was in the area about twice a month and for many years she would work on me when she came to town. This started during the late summer after my breast cancer surgery, so Shari saw me immediately before, during, and after the laryngectomy and radiation.

She had never worked with one of us before, but she found ways to get my muscles back in shape and for me to keep everything moving. As I progressed into using a TEP voice, always using my left hand to occlude, she found exactly where it was affecting me. As I did new movements, she would find what was binding up.

I remember one day when she worked on my chest and found the really sore spots. I didn't even have a voice to groan! But when I got off of the table, I could breathe easily. She was my miracle worker, and her four articles follow.

The Right Touch:
Self-Massage for Laryngectomees and Head and Neck Patients

Shari Aizenman

Touch has always been important. I'm sure that even the dinosaurs had a way of nurturing their young. Research shows that primates would rather live without food than without touch. Being a massage therapist, a primary and secondary caregiver to hundreds of willing participants, I have done my own bit of "research." Touch is just plain good for you. It is necessary to the growth and survival of the body, mind, and spirit.

Many grow up in an environment where touch is not a part of nurturing but we know we can comfort another person by placing a hand on a shoulder. A simple hug can help a person in grief or fear and providing touch is an act of loving or caring. Self massage is a way of hugging yourself. Your sore shoulder feels better if it is massaged and the rest of your body knows you are taking care of yourself and is comforted.

Being a massage therapist for fifteen years has been a gift for me. I have touched so many different types of people with totally different needs.

Eight years ago, a special person named Pat was re-introduced to me. I had first met her at a time when she and my father dated many years before and now her son, a client of mine, recommended that his mother come in as she had been diagnosed with and treated for breast

cancer. So we met again and our journey in healing began.

During that first year, we touched our way through a second cancer that resulted in her laryngectomy. The next path was before us and we walked together on this journey. Massage has been an important part of Pat's healing, and an education in self-care. I will share some of the basics of touch and stretching that hopefully will for you as well.

Recognize your tools, as they are many and varied. When we think of massage, we always think of the hands as our tools, but as we age, sometimes arthritis and other maladies may hinder our ability to use our hands to massage. There are many massage tools available on the market, as well as some you may have in your home. Do your research to find the right tools for you. In this massage session, your hands are your tools.

Remember the basics of massage. Do not massage swollen, bruised, or open skin. You may want to ask your physician if there is any reason why you should not be doing self-massage.

The right touch. Give your hands a little stretch. Stretching your hands in preparation is important. Lengthen your arm to lock your elbow and gently pull back on each of your fingers and your thumb. Then bend each finger, stretch your hand towards your palm. Shake your hands, bend each at the wrist, and spread your fingers as wide as possible. Repeat this process. You're ready! Remember to take breaks as often as needed so your hands don't tire.

You'll be sitting for the first part of the session. Keep your spine as supported and erect as possible and

your feet planted firmly on the floor. Remember to breathe! Reach across your chest with your right arm, resting your arm on your chest and placing your right hand on your left shoulder. Cradle the right elbow with your left hand for support. Gently begin kneading the tissues of your left shoulder, as softly or firmly as is in your comfort zone. You can make circles with your fingers or knuckles, squeeze with your fingers and thumb, or just use pressure to compress the tissues. Work your way up the back of your neck, using the cradling hand to assist in pushing the right arm up. Grasp the back of the neck (sort of like you would a kitten) and squeeze. Hold this tension for ten seconds. Repeat. On the second squeeze, gently stretch the tissues behind your neck by tucking your chin towards your chest. Hold for ten seconds. Repeat this process on the other side.

Still sitting, lengthen your spine by gently lifting up from the top of your head. When you do this your chin should drop a little toward your chest. Gently allow your left ear to drop toward your left shoulder, stretching the tissues of the right side of your neck and shoulder. You can assist this stretch by reaching over the top of your head with your left hand and pulling the head in the same direction. Hold the stretch to the count of ten. Repeat on the right side.

Next, staying tall through your spine, turn your head toward the left as far as it can comfortably go, and assist the stretch by taking your left hand and placing it on the right side of your face, pulling your cheek toward the stretch. Hold to the count of ten. Repeat on the right side.

Now gently drop your chin to your chest. You can increase this stretch by lifting up the back of your head, lengthening your spine even more. Relax and gently allow your head to stretch back, supporting your head by placing your interlaced hands behind your neck and stretching over your hands, allowing your mouth to open and your jaw to relax. Lifting up tall from the top of your head once again, imagine you have a pencil coming out of the top of your head with the lead pointing toward the ceiling. Begin making small circles with your head, drawing imaginary concentric circles on the ceiling with the pencil. After you have drawn five circles, reverse the process, drawing large circles to small in the other direction.

Find a place to recline. Rub your hands briskly together and place them over your eyes. Hold your hands over your eyes to a count of ten. Take a couple of breaths. Gently move your hands toward your temples and rub in circles, first in one direction, then the other, moving out towards your hairline. Rub your forehead and your scalp, softly or vigorously, whichever feels best to you. Give your ears a gentle tug down and squeeze the perimeters of your ears. Stick your tongue out and make a funny face. Rub your cheeks and jaw, then under your jaw, and gently rub your throat. A little cream or lotion can help with friction. Rub your scars and let them know you care. Give your hands a little kiss and your soul will remember, until your next massage, how much love you have within.

The Right Touch II

Shari Aizenman

In this session, we'll deal with the shoulders, upper back, rib cage, and chest. In the first of this series, I mentioned the need to recognize your tools. Today we'll incorporate a tennis ball as a massage tool. You may not want to share your pet's toy, so it's better to have one designated for your use only!

In the first part of this session, you'll be sitting in a chair with a strong back. Plant your feet firmly on the ground and stretch tall from your spine, lengthening your spine vertebrae by vertebrae. Notice your breath. Keep your breathing easy and deep.

We'll begin this session with some warming up movements. Stretch your right arm above your head, reaching really high, then let your left arm follow, reaching over your head toward the ceiling. Keep your head straight and your eyes looking forward. Gently stretch your fingers, then your hands, up one at a time as if climbing a ladder. Allow your rib cage to release with these gentle stretches, and be aware of your breath. Feel your sitting bones remain in contact with the chair as you reach your arms toward the sky. Climb ten rungs on the ladder, then allow your arms to come to your sides, bringing one down at a time. Check your spine for length, and then check in with your breathing. Are you relaxed? Is more breath coming in?

Next, with your arms to your side, gently reach your right fingers toward the floor. Allow your ribs to curve toward the side and form a C shape, finally

allowing your head to follow to complete the curve. Don’t lean over so far that you lose your balance! Hold this stretch to a count of ten, slowly come back to the starting point and resting for a couple of seconds. Repeat on the left side.

When is the last time you gave yourself a big hug? Reach your right arm across your chest, and then your left arm across your chest under the right one. Give yourself a big squeeze. Then open your arms, stretching them slowly out, and with palms turned facing behind you stretch your arms as far back as you can, opening your chest as you breathe. Pull your shoulder blades together to increase the stretch. Hold to a count of ten, and then release. Bring your left arm across your chest, following with the right arm underneath, and hug yourself again. Allow your arms to stretch back as you did before. Feel your breath as your chest opens. Hold to a count of ten and release. Give your fingers, then your hands, then your arms a good shake.

What happened to the tennis ball you have? If you left it on the floor, the cat probably batted it under the couch, so dig it out. It's time to use it. It will be used here as an "active" compression tool.

Holding the tennis ball in your left hand, press it against the tissues on your upper chest, your pectoral muscles. [The pectoral muscles are two large fan shaped muscles covering the upper rib cage.] Keeping your hand relaxed, press and roll the ball slowly to compress the muscles in your chest. Use whatever pressure is comfortable for you. If you find a sore spot, by all means give it some special attention. Press the ball on these sore spots, hold, and breathe to a count of ten. Allow the

tissues to relax and soften as you press the ball into them.

Work the sternum [in the middle of the chest] and as close under your collarbone as you can. Roll and press the ball on the area of your chest where your arm meets your torso. [Stay away from your underarm.] You can even roll the ball on your rib cage. Switch the ball into your right hand BEFORE your left hand gets tired. Remember, the name of this game is Feel Really Good!!

Try this: place the ball between your back and the chair back. Press gently and allow the tissues of your back to relax around the ball. Hold to a count of fifteen. Release and move the ball to the next spot, repeating the process of compressing and releasing, covering as much of your back as you can comfortably reach.

The tennis ball has a variety of uses. It will be used here as a "passive" compression tool. Try this out, and if the pressure is too hard for you, place a folded towel between you and the ball.

Find a comfortable place to lie on the floor. A carpeted area is best. Have the tennis ball close by. Gently lower yourself to the floor, working your way to a lie-down-with-your-knees-bent-up position, feet flat on the floor. Take a few breaths and really relax. The clue to make this next massage work is patience. Roll over a little to your left and place the ball under your back on the right side. You can work any area of the back except directly on the spine. Use your legs to raise yourself over and then lower yourself onto the ball, allowing your body weight to do the work. As you feel the pressure of the ball between you and the floor, use your breath as a tool to allow the tight tissues to soften. Breathe into the

pressure and allow the breath to escape slowly from your chest. Feel your body mold around the ball. You can lie on the same spot until you no longer feel the ball there, or for as long as it takes for the tissues to release. When you are ready to work the next area, lift your body up with your legs and pelvis then roll one direction or another on the ball to find the next spot. Work on your back for ten to fifteen minutes, and take care when coming back to a sitting position. Slowly push yourself to standing.

The rest of this session will be done standing in a doorway. Choose an unobstructed doorway, the narrower it is the better. Stand with your toes at the outside of the door opening. Hold your palms together twelve inches in front of your chest, the heels of your hands towards your chest, fingers pointing away from you, elbows out to the side. Relax your shoulders and breathe.

On an exhale, squeeze both hands together, palms to fingertips, holding firmly to a count of ten. Then drop your arms to your sides for a count of five. Step your entire body into the doorway with one foot in front of the other. Raise your hands and arms up onto the outside of the door jamb, placing your fingers, palms, forearms, and elbows on the jamb, right at chest height. Gently lean your body onto the forward leg, doing a small easy lunge, allowing your chest to open as you move forward, stretching through your upper body and chest. Hold this stretch to a count of ten. Release your arms. Give them a shake. Relax and repeat, this time leaning forward onto the other leg. Good going! Give yourself another hug. This hug is not just to congratulate yourself, but it

relaxes the tissues you just stretched in your chest, so it's needed.

Remember that these times you give to yourself are very important in your wellness, no matter where you are in your life. Regular massage and stretching is an adjunct to your total health program!

The Right Touch III

Shari Aizenman

How do you know when it's time for a massage or time to stretch, or even if you need to do either? What are the benefits?

As I said in my first article, touch is necessary for the health of the body, mind, and spirit. There is a great deal of research that has been done on the benefits of massage and stretching. The two main physical benefits of both are increased circulation and increased mobility in the soft and bony structures of the body. The psychological benefits are increased relaxation, a sense of vitality, and heightened awareness. The spiritual benefits are a better connection with yourself and a sense of serenity.

Stretching: isn't that something we do naturally do? When my clients ask, "When is the best time to stretch?" I refer them to a lesson I learned from my cat. I notice whenever she gets up from a lying down position she always stretches out! How smart is that?

There is no wrong time to stretch. Anytime there's physical labor involved is a good time to stretch. How long should you stretch? Here's a formula. Allow five minutes of stretching time for each forty-five minutes of activity. The more arduous the activity, the more stretching time you need to add to the formula. This includes working at a computer, at a desk job, or sitting in front of the TV. Massage is another anytime activity. Make it an everyday, anytime routine.

In this session, we will incorporate the hips, ribs, and lower back, as well as the diaphragm (your breathing muscle). Remember that these sessions are designed for you as a laryngectomee, but anyone can benefit from them.

You will need a bath towel, rolled up tightly lengthwise, for the end of this session. You can roll two towels together if necessary. See how it feels with one, and then decide if you want the second.

This session will be done lying on a firm surface, preferably the floor or on your bed if necessary. If you have lower back problems, place a firm pillow under your knees. You may choose to put a very small pillow or folded hand towel under your head, but nothing much larger. Begin by warming up. Gently ease yourself to the floor and relax. Breathe slowly and comfortably.

Reach one arm over your head and let it lie on the floor above you, then follow with the other. If you have trouble getting your arm flat on the floor, use folded towels to prop them at a comfortable level. Reach your right hand up, as if climbing a ladder. Then release your ribs as you stretch and reach up for the ladder with the left hand. Breathe and allow your body to relax with the stretch. Reach up and release ten times on each side, alternating right and left.

Slide your arms down to your sides, stretching downward. When your hands are by your sides, turn your palms facing down. Rest your arms at your sides for a moment. Reach your right hand down toward your right foot, sliding your palm by the side of your leg along the floor, allowing your head to gently roll to the right as your body gently curves to the right. Reach

down as far as feels comfortable for you and hold to a count of ten. Breathe into the left side of your chest and rib cage, feeling the expansion on the left side as you inhale. Bring your right hand back to the starting point and repeat on the left side. Allow yourself plenty of time and reach down ten times on each side, alternating right and left. Remember to allow your head to roll and your neck to be soft and flexible with your movements. Take a moment to notice any changes in your breathing and see if your chest is more relaxed.

Now it is time to incorporate your legs. Position your legs so your kneecaps are pointing towards the ceiling and your toes are pointing straight up. Gently step down with the heel of your right foot, then slide your heel on the floor away from your buttocks, bringing your toes headward, straightening and lengthening your leg, making it longer. Breathe as you step down toward the far wall. Hold for five seconds. Release and straighten your left leg, stepping down with your left heel as you gain length, allowing your lower back to release to allow you even more length in your leg. Hold to the count of ten. Once again, step down ten times with each leg, alternating right to left, rocking through your pelvis as one hip goes up and the other down, a natural movement that comes with the stretch.

Notice as you slowly move: is there a place that is hindering your movement? If so, can you locate that spot? If it's within reach, stop your movement and gently massage the area for a few seconds with your hands or fingers. You can massage those harder-to-reach places by placing a tennis ball between the spot and the floor

and gently releasing the tissues as you lie on the ball. Then continue with your movements.

Are you ready to put it all together? Once again, place your arms above your head, one at a time, resting them on the floor. Give yourself time to practice this and be patient. Breathe. Reach up for the rung of the ladder with your right hand, lengthening your arm, and step down with your right heel, lengthening your leg at the same time. Feel your ribs open on the right side and your chest fill with healing breath as you stretch upward and downward. Allow your head to roll in the direction that feels natural for it. Release after five seconds and as you release the right side, reach up and down with the left hand and heel. Breathe. Are your hips going up and down, your shoulders rocking on your spine? Continue this healthy stretch for as long as it feels good to you.

Roll over on your side and push yourself up to a sitting position. Retrieve your rolled towel and place it lengthwise next to you. You will need to get back to the floor, lowering yourself onto the towel, so the towel runs the length of your spine, on your spine, from the bottom of the curve in your neck to your tailbone. Allow yourself time to adjust to the towel's presence. Your breath is the tool you'll use to relax, allowing the tissues of your spine to relax over the towel with each exhale.

Gently draw one leg up at a time, coming to the lie-down-with-your-knees-bent-up position. With each of these stretches, you will repeat three times on each side. Slowly draw your left knee toward your chest, pressing your lower back and sacrum (the triangular-shaped bone at the base of your spine) down onto the towel as your knee comes up. You may choose to wrap your interlaced

fingers around your knee, gently increasing the stretch. Hold your knee up for ten seconds, release your lower back, then lower your leg. Repeat on the other side.

Squeezing your knees together, gently allow your knees to fall a little bit to the right side, stretching out your left lower back, maintaining your balance on the towel. Hold for ten seconds and repeat on the other side. Finally, raise your right leg and straighten it at the knee with the sole of your foot facing the ceiling. See if you can step up toward the ceiling. Bring your leg back to the bent position and place your foot back on the floor, then repeat on your left side. Roll to one side and come to a sitting position, then when you're ready come up to a standing position.

Rub your hands together briskly for five seconds. Give yourself a hug for a job well done and this notifies your body that the session is over.

The Right Touch IV

Shari Aizenman

In the previous three articles on stretching and self-massage, we covered the chest and back, ribs and breathing apparatus, shoulders and neck. We discussed that there are various tools to use in massage and even incorporated a tennis ball and a towel in your stretches. You may want to consider reading, or having someone read, these sessions into a tape recorder and play them back as you stretch or do self-massage. If you do so, then be sure to do it slowly, giving yourself time to do each of the movements or exercises.

In this session, we will focus directly on healing on and around the laryngectomy site. As you may know, there are different types of laryngectomy surgeries, and each has its own purpose and focus. But these surgeries have in common the trauma on the tissues of the neck and surrounding areas. Lymph nodes and glands are often removed, destroyed, or aggravated. There is scar tissue, and radiation may have taken its toll on the skin and underlying tissues. I have found that the usual self-care information offered to post-surgery patients does not include self-massage. Remember that this is YOUR body and YOU are in charge of it. It's time to really explore and discover what your particular needs are around your surgery site.

To do this massage, you will need some cream or lotion. I prefer to use cocoa butter, which in its pure form is solid. Cocoa butter is very emollient and penetrates into the tissues well, allowing for the perfect amount of

friction necessary to do the massage. Pure cocoa butter is available at the beauty supply store and at most pharmacies. If you cannot find it, any cream is better than none.

In today's massage, your hands will be your tools. You will sit in a very comfortable chair (a recliner is great) for this session. You can also prop yourself in the bed or on the sofa with lots of cushions or pillows for support. First start with a little warm up exercise. Place the palms of your hands together about six inches in front of your chest, fingers matching, and point your fingers away from you. Your thumbs are pointing up. Spread your hands out, fingers still matching. See how wide you can make the spaces between your fingers. Use the fingers on your right hand to gently stretch the fingers on your left hand by pushing them back, giving a good stretch through the wrist, and then reverse the stretch. Hold to a count of ten on each side and repeat three times. Give your hands a good shake out. Gently pull each finger and each of your thumbs. Pinch all the way around the ends of your fingertips. Clap twice. Give your hands a brisk rub on both the palm and the back side. Now on to the massage.

We will begin with a relaxation exercise. Reclining comfortably, close your eyes and watch your breath. Without changing your breath, you might notice that it gets slower and more regular by just watching it. Allow yourself a few breaths to let go of anything that is distracting you. Allow thoughts and images to come into the forefront of your mind, and then allow them to escape by breathing them out with a breath of relaxing air. You might want to imagine that your lungs are filled

by a large balloon, and that balloon fills from the top to the middle to the bottom as you breathe in, and that the balloon empties from bottom to middle to top as you breathe out. Allow yourself a few breaths to get the sensation of letting go of any stress as you breathe out, and filling up with a sense of calm, relaxing energy as you breathe in. Fill up and let go. Give yourself a few moments to deal with the images that come into your mind, letting them go as you breathe and getting in touch with a sense of inner calm.

When you feel that you have let go of as many distractions as you can, turn your attention to the area around your surgical site. Have you ever explored the soft tissues there? Reach up and feel the area from behind your ears at your hairline around to your jaw. Gently rub in small circles, holding down the skin, rubbing the tissues just underneath the skin. Feel the bony structures and get a sense of what your particular tissues feel like. Are there sore spots? Give your ears a tug in all directions and even stick your fingertips inside and give them a rub. Use your thumbs to rub underneath your jaw right on the bone until you reach the chin. Are there sore spots there?

Now, explore the area on the front of your neck, paying particular attention to your scar, still gently rubbing in small circles. Massaging scar tissue is especially important because scar tissue can bind tissues together, impeding free movement between structures. After exploring your scar, work your way around the stoma site, feeling your collar bones, over and underneath. Do you feel as if you know your throat a little better already?

Time for the real massage. If you're using solid cocoa butter, you will need to rub it between your hands to warm it up, melting it enough to feel a little creamy. If you are using another cream or lotion, always rub it in your hands to warm it up first. The stages of this massage are palpate (checking the tissues as in the previous paragraph), warm the tissues, apply friction, and cleanse the tissues with sweeping movements. Palpation, warming the tissues, and friction can be done in any direction, while sweeping movements will always go top to bottom.

To warm the tissues prior to friction, use the pads and tips of your fingers. I suggest using both hands for this part of the massage. Use just enough lotion to allow your hands to slide over the tissues, being aware that too much will not allow you to feel what is under the skin, the area we want to really massage. Not using enough will cause too much friction. You can always add or wipe away lotion.

We will begin by using the hands to spread it over the entire area from the chin, down the front of the neck, to underneath the collar bones (clavicles), and out to the sides of the throat, even with the earlobes. A note of caution: do not press deeply into any area on the front of the throat. You have major arteries and veins there and we want to avoid any pressure that might hamper blood movement.

Rub your lubricant starting under your ears, working your way to under your chin, gently pulling the tissues forward. Stroke this area five times, ear to chin, spreading the cream evenly. Then using the pads and tips of your fingers, warm the tissues from the sides of your

neck into your scar by gently pulling the tissues toward the centerline on your throat. Reach across your throat with your right hand, pulling the tissues from the left side toward the center, all the way from the outer edge of your collarbone to your stoma. Stroke each area five times, feeling each stroke a bit deeper as you go. Then repeat with your left hand on the right side. Give your hands a rest and shake them out.

The next part of the massage may feel strange, but with practice it will become more comfortable with time. Support your right elbow in your left palm, laying your right arm across your chest. Using your right hand, gently pinch the tissues on your neck together, the amount of skin you can pinch between two fingers and your thumb, gently rolling the tissues together, lifting the skin away from the underlying tissues. Breathe. Notice that some areas are more tender than others. These areas need special attention. Rub them for a bit longer until the tenderness subsides. Work around to your scar and give it special attention. Lifting, squeezing, and creating friction with the scar tissue allows blood flow to the scar to increase, which in turn increases mobility of the scar itself. Switch hands as needed so your hands don't tire. Spend several minutes working this area, then turn your attention to your collar bones.

Using your fingertips, hold down the skin and rub the deeper tissues. One at a time and cradling your elbow in your opposite hand, rub the left collarbone with your right fingertips, then allow your fingers to dip into the area above and beneath the bone. Sensitive? Rub in this area as deeply as is comfortable from the stoma to the

shoulder, then switch sides. Any area that is particularly sore can have some extra attention.

Remember to breathe and take breaks as needed to keep your hands from tiring.

The sweeping motions in this session are as important as any massage you will ever do. Begin by using your entire right hand, crossed over to the left side. The sweeping motion will cover from under the ear all the way over and under the clavicle to the fold at the armpit, where there are lymph ducts. Sweep down only. Imagine that you are using a squeegee to push water off a windshield. Make ten strokes down the left side of the neck, over the clavicle, toward the fold at the armpit. Shake that hand five times when you are finished. Change hands and repeat with the left hand crossed over the right side. Shake that hand out when you have finished. Give the backs of your hands a brisk rub, then give yourself a pat on the back for a gift well given and received.

Oh, My God! I Can't Swallow!

By David L. "Dutch" Helms

In November 2004, I began to notice some increased difficulty in swallowing chewed foods. Foods that had for the past ten years gone down easily now seemed to be getting stuck in my throat and required that I swallow some liquids with them in order get them down. I spent some time with an SLP who counseled me on the situation. I made some minor changes in HOW I ate and things seemed to stabilize, if not actually improve.

The situation remained basically unchanged until around the middle of April 2005 when almost overnight my swallowing difficulties seemed to increase significantly with each passing day. Suddenly, chewing and swallowing meats was virtually impossible, then salads, breakfast cereals, and even soft-boiled eggs became too difficult. I was also beginning to notice that I was having increased difficulty voicing clearly with my TEP/prosthesis; my normal volume was decreasing and the air pressure required to speak was increasing. By early May, I could barely speak with my prosthesis and could hardly swallow even thin liquids.

The research I had done convinced me that one of two things had happened: (1) my esophagus had suddenly decided to narrow and close up and might require esophageal dilation, or (2) I had developed a NEW cancer – this time esophageal cancer somewhere between the base of my tongue and just above my tracheoesophageal puncture site. While my head wanted

to believe the first option, my gut was telling me option two was the more likely culprit. I was concerned, to put it mildly.

By early May, swallowing anything was problematic, even my own saliva. Being a laryngectomee, I could of course still breathe just fine. I composed a two-page letter to my primary physician describing my symptoms and the history of the problem, and faxed it to his office, requesting an emergency appointment with him on Monday. Throughout the remainder of that day I tried to swallow some very thin soups, basically chicken broth. By Sunday, my esophagus was almost totally blocked and voicing with my prosthesis was now impossible. I dropped an update fax to my doctor to keep him up to speed and spent the rest of the day trying to get something down with little success.

Monday, my doctor tried to get me an urgent referral to a qualified gastroenterologist (a common HMO story). On Tuesday, I was in the office of Gastroenterology Consultants for a quick exam. The doctor's initial reaction was that it was not a new esophageal cancer but merely (merely to him, maybe) a narrowing of the esophagus caused by tissue damage done during my radiation treatments years ago. He juggled his calendar and scheduled me for a esophagogastroduodenoscopy (EDG) under fluoroscopic support for Thursday at a hospital.

The EDG experience was not as bad as I had thought it would be. I checked into the clinic, undressed, and was given a hospital gown and a bed. They started an IV and did some other minor preparations, then rolled

me into the OR. After they ensured air flow to my stoma, they had me roll on my left side, started IV Demerol, stuck a small EDG guide into my mouth and promptly watched me drift off. I awoke about forty-five minutes later, feeling groggy but fine.

The doctor had discovered a marked esophageal stricture, most likely post-radiation in origin, located in the proximal esophagus. He performed a dilatation followed by a complete EDG, and everything else (throat through stomach) appeared normal. He confirmed that my esophagus was almost totally closed but he had opened it up quite a bit with the dilatation.

Several hours later, I was back at home. I could now eat things and swallow them! For the first few days, I stuck to soft foods – potato soup, cottage cheese, and puddings, but it was wonderful. I progressed easily to chili with beans, baked potatoes with sour cream, bacon bits and butter, and more. The only problem, other than a minor sore throat easily controlled with liquid Tylenol, was I still could not speak properly with my prosthesis, probably due to swelling around or near the puncture. I was scheduled for a follow-up EGD and dilatation in one week.

As promised, his office juggled his schedule again and told me to report early on Wednesday. The only problem was that his staff forgot to tell him about the schedule change, so while I was there at the appointed time, the doctor was not. After many phone calls, we rescheduled for later in the day and a second procedure was done, routinely and without problems. I asked if GERD could have caused it and he said there were no signs of that in the proximal esophagus. He did notice

some tissues in my distal esophagus (just above the stomach) that might indicate potential Barrett's Esophagus, a disorder in which the lining of the esophagus has cellular changes caused by irritation from stomach acid.

This being the case, Dr. Schneider took a biopsy of my distal esophagus during the 2nd EGD. He also took a photo of the area and of where my prosthesis enters the esophageal wall to assist my SLP in case a prosthetic re-sizing was necessary.

By day two, the sore throat had largely passed and I could again eat almost normally and I could actually begin to speak a little bit with my prosthesis. The voice was breathy, rough, and bubbly, but it was a voice. It was now time to just wait and see what happened after the tissues "settled down" and get the results of the distal esophageal biopsy.

The biopsy came back clean and I spent the next three weeks waiting for the swelling to subside and the tissues to stabilize while talking to some experts and veterans of the procedure on what to do about my problem. At the top of their lists of advice was patience and the eventual use of finger pressure on a spot on the outside of my throat while occluding the stoma, providing a return to some kind of TEP/prosthesis voice. In the interim, my trusty Servox served me well and often.

By mid-June, my swallowing difficulties resurfaced and I was back to a liquid diet. A third EGD/dilation was scheduled on June 24th and my esophagus was again stretched and reopened, followed by a fourth EGD/dilation a week later. During these dilations, it was

confirmed that the tissue blocking the esophagus was not cancerous but rather simply scar tissue from my radiation treatments back in 1993. Still, this tissue was proving a tough nut to crack.

I was still without my normal TEP/prosthesis speech and getting by with my Servox. Given the choice, I would rather be able to eat and speak with a Servox than not able to eat normally and speak via the prosthesis. As much as I love TEP speech, I love good and varied foods much better!

So, I shall just have to see what the future brings: an esophagus that remains relatively open for a while, more dilations down the road, or some other type of intervention that would produce a more long-term positive result. After four EGDs and dilations, I now consider them as routine as brushing my teeth (while not quite as pleasant). You can rest assured I will be doing all I can to make sure my enjoyment of pizza, fried chicken, and steaks does not come to end. The ultimate goal is to return to near normal eating and swallowing, regardless of what my final voice option may be. Priorities are simply that...priorities! I can report that after dilations one, two, and three, my esophagus quickly started to close up again. After this fourth dilation, my esophagus did not do so and has remained relatively open. I am “knocking on wood” that it remains open.

FOLLOW UP ARTICLE:

After a fifth dilation and evaluation in August, my medical team requested a meeting with me the next day. At that meeting, they went through the case history and noted their strong conviction that, while the stricture was

of some concern, the real problem was the ongoing Barrett's Esophagus and tissue "changes" they were observing. Apparently, after years of taking anti-GERD medications, the condition had worsened dramatically. They recommended priority surgical intervention and cautioned me not to wait.

On August 20th, I went in for some pre-op photodynamic red laser light therapy (PDT) preparation and counseling. The next day, I checked into the hospital so they could effectively monitor my immediate pre-op intake. My surgery was primarily to address the GERD/ Barrett's Esophagus issues. I was rolled down to surgery around 5:30 the next morning, and found myself alive, conscious, and functional by 11:30, back in my room and feeling relatively fine. They had repaired a small hiatal hernia, did a laparoscopic fundoplication, an anti-GERD surgery, treated two small tissue areas in the lower esophagus with low dose photodynamic laser light therapy, and also re-dilated the upper esophageal stricture. All the procedures were deemed successful.

For those not familiar with PDT, photodynamic laser therapy, here’s how it works. Patients are given an injection of a photosensitizing drug called porfimer sodium (Photofrin) and cells in the body absorb this drug. Normal cells get rid of it, but the drug tends to collect in premalignant and malignant cells. Two days after the injection of Photofrin, physicians insert an endoscope into the sedated patient’s esophagus. An endoscope is a thin, flexible tube with a miniature camera on its tip. Physicians deliver a specific wavelength of red laser light (not heat) through the endoscope to the targeted cells. The laser light destroys

the Photofrin-containing cells. Normal esophageal cells grow back in their place.

The in-hospital recovery period was short and routine. I had awakened to discover a flexible tube inserted into my nose and routed down into the stomach to hold the passage open during the fundoplication procedure and for a short time post-op. This tube was removed shortly after I returned to my room and with an absolute minimum of discomfort. The most significant recovery pain I experienced came from the five small laparoscopic incisions in my abdomen. I joked that it felt like five small 22-caliber bullets had been shot into my gut! They did, however, have me up walking around later that first night and more so each day afterwards. It was really not pain, but was more accurately moderate then slight discomfort.

I was initially on some IVs and given only small amounts of water to drink. By the end of day three, the IVs had been pulled and I was on a liquid diet of Ensure and a couple of cans of smuggled Slimfast, all of which went down fairly easily and stayed down well. I was kept for a few days of observation and then was discharged early Thursday morning at which time I returned home with a minor sore throat and a tender abdomen. I was provided with the services of a home health nurse who checked in on me every day for the following week, but all was routine.

I maintained a liquid-only diet for about ten days post-op, when I was authorized to move up to soft foods such as thick soups, mashed potatoes, creamed items, soggy cereals, and puddings. After that, it was on to chewy foods, such as casseroles, well-cooked rice and

veggies, baked potatoes, tender fish, and well-chewed chicken. I was again cautioned to continue to avoid highly-seasoned and spicy foods (so much for my Taco Bell favorites), as well as tough to chew items such as steaks, fried chicken, pork chops, or roasts. While somewhat boring, this transition back into normal eating habits made a lot of sense. I had been warned that I might experience some discomforting side effects from the fundoplication surgery, such as difficulty with swallowing bloating or discomfort from gas buildup because I would not be able to burp. None of these occurred.

There was, though, another minor side effect of the procedures. As a result of the pre-op injection of Photofrin, required for the photodynamic laser procedure, I was warned that my system would be very light-sensitive for four to six weeks after the procedure. I was cautioned to avoid direct sunlight and bright lights, and to wear sunglasses when outdoors. Not being very outdoorsy at this stage of my life, this side effect was minimally intrusive for me.

After a follow-up exam, my medical team determined that the Barrett's Esophagus problem appeared under control but recommended that a three to six month period of treatment with 20mg daily of omeprazole (Prilosec) be maintained to fully suppress GERD production in that area so as to ensure the Barrett's tissues are totally gone and replaced by normal squamous epithelium tissues.

They recommended follow-up endoscopies over the next year or so to confirm these findings and cautioned that the esophageal stricture might again try to

close, so future dilatations might well be required. Keeping the esophagus permanently open via the insertion of a stent had to be ruled out because of the stricture's location. It was too close to the base of the tongue, and if placed there it would significantly interfere with swallowing. As usual after dilations, my TEP/prosthesis voice was still absent, but should return once the tissues in the TE segment settle back down. At least, that is the current hope.

At the end of the follow-up exam, I was told I could now slowly ease myself back into my normal eating habits. Upon returning home, using the good judgment often exhibited by fighter pilots, I promptly called Pizza Hut and ordered a medium hand-tossed pizza with extra pepperoni, Italian sausage, cheese, and sauce. It was delicious, went down just fine and stayed down as well. This will be followed later by visits to Taco Bell and the infamous Texas What-A-Burger!

So all in all, the procedures were successful and well tolerated. The pain was absolutely minimal (after the first few days, but drugs helped a lot), and the at-home recovery period went just fine. The major downside to this medical adventure was that I had to miss IAL 2005 in Boston, the annual WebWhispers reception and banquet, and the follow-up WebWhispers cruise to New England and Canada. However, as we all know, compromises must be made on occasion. As much as I missed all those festivities and missed meeting old and new friends and acquaintances, I feel I made the right decision to proceed with these medical procedures instead.

Large Cave Discovered In Man's Neck!

Dutch Helms

Beginning in mid-January 2006 as a "pin-prick size" hole, a new post-op and post-radiation "fistula" suddenly developed in my neck, just above the top rim of my stoma. Several observers claimed this discovery rivals that of finding Mammoth Cave in Kentucky! Such fistulas (holes) often develop due to tissue damage after radiation, when the tissue loses vital blood supply then slowly dies off, creating "dead space" between the esophagus and the outer skin. (Note: The opening narrows significantly as it progresses inward and is very small at the esophageal end.) While some fistulas can be closed via conservative surgery, others require more extensive treatment such as "forearm flap surgery," moving healthy tissues from one part of thebody into the fistula area, sewing it into place, and then allowing the entire area to heal.

The fistula is located just above the stoma and is about 1 3/4" high and about 1 1/4" wide. Amazingly, it developed about twelve and a half years after my radiation treatments ended in September 1993. Normally, I cover the fistula with cotton pads held in place with tape to prevent undue drainage and leakage. At the time of this writing, I'm waiting for a final surgical repair to take place in early March, hopefully at MD Anderson in Houston. One conservative surgical attempt in early February failed to close the fistula. Contrary to what some have said, it is NOT a second stoma.

WEBWHISPERS

The following section introduces you to the wonderful organization that is available for anyone with an interest in throat cancer. The online organization is a source of education, information, and support to anyone touched by the condition.

Dutch Helms and the Larynx Cancer Site

In December 1996, there were ten laryngectomees from across the US and two from the UK who turned to their computers in hopes of being able to find any information about breathing, talking, and eating. Some of these people had never seen another person who had these same problems. That day, they found a newly added site about larynx cancer. It listed a few places to go for information, and an email address with a request for other people who'd had this surgery to be a source of information for each other.

It was a miracle that there were others of this new species, laryngectomees. They could write an email to someone who would understand and get an answer right away. For most, it gave them a reason to get up in the morning and look for their new friends, a new reason to live and hope for a better life. They not only found each other, they found a family, led by a man named Dutch.

That family grew in the first year to 87 laryngectomees, five otolaryngologists, one radiation oncologist, fifteen SLPs, one head & neck nurse, and about twenty caregivers. We were all pioneers.

Dutch Helms was the type of man who did not mind change in order to make things better, who would rather try something than accept the status quo, and was not afraid to tackle the unknown.

If we tried something that did not work, he was the kind to ask for more ideas. Intelligent and possessing the ability to make swift decisions had made him perfect as a jet pilot, and a perfect leader for us in deciding what was

needed in a support group for laryngectomees.

Here is how he came to be there for us.

Dutch served as a pilot in the US Air Force for 21 years and rose to the rank of lieutenant colonel. He served one tour in Vietnam attached to the 81st Airborne Division as a Forward Aircraft Controller. During Dutch's tour in Vietnam, he was awarded the Distinguished Flying Cross for bravery in action. Following that, he was appointed military attache at the US embassy in Bonn, Germany, due to his fluency in the language and his ability to negotiate with other allied officers. After a long separation from his wife he was divorced, but stayed busy and loved his work. During his service, he had been a military jet pilot, negotiator, teacher, instructor, coach, emcee for events, narrator, briefer, and discussion leader. He loved to sing in choirs, barbershop quartets and choruses. He had planned to marry again but when that was not to be and he was devastated when the date was cancelled three weeks before the wedding.

Shortly thereafter, while in Bonn, he was diagnosed with laryngeal cancer and radiation was recommended. He was medivaced to the USAF Cancer Treatment Center, at Lackland AFB, Texas. It was a great facility, but he had no friends or family near, just his doctors and nurses for support. No one told him about the IAL (International Association of Laryngectomees) and the existence of laryngectomee support groups, so there was no support help during the radiation treatments. When the radiation failed to arrest the cancer, Dutch became severely depressed. He later told us he could not face the thought of going through laryngectomy surgery and spending the rest of his life with no voice and a hole in

his neck. Up until that point, his entire life had been about talking and singing. He simply couldn't think of a reason to live, and spent a month in treatment to help him get a grip on life.

After the surgery, Dutch's best friend since junior high school offered him the opportunity to live with him, his wife, and family while he recovered. This gesture and experience really saved his life and finally helped him out of most of the depression. It forced him to be with people, to talk, to get accustomed to using his new TEP voice in all sorts of social situations. He went shopping at the mall, ordered pizzas over the phone, and was there when they entertained their other friends. In essence, living with them forced him to become re-engaged in living. Having the computer with its games and the Internet not only provided entertainment and education possibilities, but also the tools to learn new skills.

By 1996, Dutch was comfortable with being a laryngectomee, living alone in his own place near his friends in Houston, Texas. He'd learned enough about his first computer to build a personal website with genealogy pages, pictures of the collectable soldiers he had painstakingly painted, and webpages of other personal interests. Because he had not met other laryngectomees, he decided that he would add a few pages dedicated solely to larynx cancer. Thinking he might be able to use this to reach out to the world, he made links to the few places on the Internet that had special information about laryngectomy treatments. So in late 1996, he had some informational pages ready and he invited others to come visit. His request was basically, "Is there anyone else out there who would like to exchange emails about being a

laryngectomee?"

Within the month, he got an answer from a man in Texas, someone from England, others in Alabama and California, and more followed. They had computers and were laryngectomees, pretty much alone in their areas, and were looking for friends and answers. They found both on Dutch's larynx cancer site. By January 1st, 1997, Dutch had been joined by twelve other laryngectomees.

No one could have pictured what this would become, a person-to-person contact over the Internet that would create friendships among hundreds and then thousands of people with similar problems. This was the snowball rolling down from the mountaintop, and taking on a life of its own. As the membership grew, the ways of making contact changed. Dutch adapted each new change to make the group, which became WebWhispers in 1998, easier to find, simpler to use, and more educational.

As others joined, they brought new ideas. As Dutch expanded the web site, adding new sections and more help for laryngectomees, the email list of names became a ListServ, enabling the contact of a whole group of individual members using just one simple address.

During all of this time, as other volunteers joined and took over responsibilities, Dutch remained the webmaster and listmaster, still taking care of all of the mechanics of what grew into a huge website and a large, ever growing, membership. One man planted a seed and tended it as it grew.

Building WebWhispers

I heard about Dutch's new site in early 1997 and told our local support group about it. It was so unusual and exciting to be able to email others and discuss our similarities. When I joined, Dutch sent a copy of the email he had sent out that day with names, email addresses, and locations of the members. There were sixty-seven patient members at that time, some caregivers, and a mixture of doctors, nurses, and speech therapists who acted as advisors. There were a few vendors there, happy at the prospect of a group of us getting together online.

I later told Dutch about Larynx-C, a site run by ACOR that I had found in February. He joined, and posted a notice in Larynx-C describing his own site.

"As part of my Home Pages on the Internet, and a laryngectomee since 1993, I have created several pages dedicated solely to the subject area of Larynx Cancer."

This is how Dutch's group grew, by word of mouth and a few emails going to sites where we might find interested people. I wrote about it in HeadLines, which had a pretty good circulation through the American Cancer Society, and it was shared on the CompuServe cancer forum. Local laryngectomees told others, as did other clubs with their contacts. Computers were new to people who were typically of an age to need a laryngectomy, and some were able to join through their children's computers. But many had no access. The first

Christmas brought us a new influx of online members who knew exactly what they wanted for Christmas: email!

A few months into 1998 we realized we had a wonderful problem: our emails were becoming impossible to control. To send an email to the group, a member had to address it to each of our more than one hundred members so it would come in to each member's email box with more than a half page just of addresses. Often, the message was simply a reply to a description of a problem, and the text would say, "I agree." It ate up space and time. Other members complained when we got long messages that said almost nothing and used up expensive download time.

It cost a lot of money to stay online and download messages, especially since the computers were so slow at that time. I paid $9.95 each month for CompuServe and I could go online for a total of 5 hours a month. If I went over, it was $2.95 per hour. I could not afford that so I saved those minutes by doing the fastest download I could and then got off line to read and answer.

I mentioned this problem to my son Scott, who was the nearest thing to a computer guru I knew. Before the comment was out of my mouth, he said, "You need a listserv."

Of course, I didn't understand what that was and Scott explained that we could put as many addresses as we wished on a service and with addressing an email to one central address, the service would send that email out to all of the others enrolled. Dutch was a man of action and as soon as I told him, he asked where he could find a service. Scott sent us a few and, as it happened, the top

one on the list was in Houston, right down the road from where Dutch lived. We were signed up the next day.

We needed a name for our list, and Dutch asked for suggestions. The name WebWhispers was chosen. He never could remember who came up with the name. Our email distribution list was set up immediately with that name and it became our organization name. We needed a logo and asked the list for submissions of ideas. Len Librizzi (one of the first larys I met online at Compuserve) submitted a beautiful logo from his daughter, who was into graphic arts. It was a world with a computer profile on each side, with WW leading from one computer to the other. It was a graphic of exactly what we do. We loved it and it still represents us.

South Carolina Conference August 2001

Fellow Webbies,

Just a quick note from the "right coast" at Myrtle Beach. The IAL is set to put on a great program over the next few days amid super accommodations and spectacular ocean front views. The weather appears to be cooperating, sunny, and not too hot nor too humid!

We had a super meet and greet reception tonight, a three-hour indoor/outdoor affair with hundreds of laryngectomees and caregivers, many of them WW members finally matching faces to email addresses. It was a super spread, with lots to drink, lots to eat, and lots of folks to get to know and to finally talk face to face.

The annual meeting program starts in earnest tomorrow. We'll miss those of you who could not come this year but will hope to see you in 2002 in Vancouver, British Columbia, Canada, and maybe even some of you on the follow-up WebWhispers cruise through the Alaskan Inside Passage.

Greetings from all the WW here to all of you out there! God bless!

Dutch

The South Carolina people really supported the IAL

coming there. Our own WW dinner had 125 attending, and that's all the room would hold. One of our Alabama members, Charles Lamar, had made a donation in order for us to present a special award—the Casey-Cooper, named after our first two presidents—for the "Laryngectomee of the Year 2001." We were proud to present it to Dutch, who had been the leader in putting us all together.

At that time, WW plans included improvements in our activities and more services each year. Our secretary, Bob Hodge, made arrangements for us to have a new brochure printed by a friend who had lost his wife to cancer, and he generously did not charge us for the design and the first printing. We started with this as the tool to get the word out. Many of the biggest and most well-known hospitals in the country were going to hand our brochures out to laryngectomees. And of course, people were finding us through our website.

For the next year, we had planned a seven-day Alaskan cruise leaving from Vancouver after the annual meeting. We had large numbers of people planning for both the cruise and the meeting.

We had already registered so many for the cruise when the horrifying attacks of 9/11 happened. We were in shock, as was the rest of the country, and no one was thinking of planning for next year. We mourned as everyone else did and discussed on our list what damage some of those survivors would sustain in throat and lungs with the unknown substances they breathed in. Those of us who remembered Pearl Harbor will never forget it, and

September 11th will be remembered the same way.

The world of cruising rebounded because the industry was concerned that the business of travel in general was going to be hurt. They cut prices sharply and our reservations were reset by our agent to half the price they had been. She knew to reserve far more cabins than we thought we would need. Our WW cruise grew, as did the IAL reservations, and we sailed with 118 people in our group on the 2002 WebWhispers Inside Passage cruise. We had members from all over the world but really became international with this cruise as laryngectomees came from other countries to join us for the double event.

Our new WW president, Murray Allan, was running the meeting for the combination of the IAL and his local host club. It was a large, successful gathering. We again had a successful dinner with large numbers and I was elated to be honored as Laryngectomy of the Year 2002.

I had made arrangements for tour buses to pick up our cruising group on Sunday morning, take us around some of the scenic areas of Vancouver, then deliver us to the ship. It was a wonderful and exciting cruise. There were so many of us that everyone on the ship said hello when they heard us talking. They knew us all and thought we were fun people!

2003 and 2004 were hard working, learning, and growing years. With all of the new members offering their problems up for discussion in WebWhispers, we had the opportunity to compare notes and learn from each

other. We became well known to doctors and SLPs across the country and they recommended us to their new patients. In some cases, we noticed products on the market, developed by the vendors, in answer to our collective complaints about something being needed. Many vendors told their new sales people to join WebWhispers immediately, and they were to read it every day as part of their job.

Dutch's Farewell – 2006

In May 2006, we were packing for the WW Alaska tour/cruise that Dutch was to miss again because of appointments, ongoing problems, and discouraging reports. He really wanted to go on that cruise, but physically he was not able.

By the end of the day, my bags were sitting by the door and I was being picked up early the next morning to head for the airport. I was waiting to hear from Dutch. At 5:30PM, I got the email from Dutch to the WW members and friends about his appointment with the head doctor on his case. We had all thought there was still a chance for some new chemo trial, and were hoping for a miracle.

As soon as Dutch wrote to let us know he was diagnosed as terminal, we had to make plans for all departments and we made them with his full knowledge and help as long as he was able. I had acted as his right hand in many activities and I had been directly working with website information for over six years, so my responsibility was the website.

I started negotiations with a knowledgeable company to design and build a new website, remembering that Dutch's original website had been started and grew as he experimented with what we needed. It was wonderful, but Dutch made all of the entries because no one else, even the professionals, knew

what to do with it.

With his permission and the rest of the board's, I signed the contract for the new one which was to contain a program that would let more us have the freedom to post on the web using a program that required no special expertise. I was to make the decisions relating to style and content placement along with cost. Len Librizzi would take care of the part of the website that needed computer education to do it. He and my son Scott advised me on the basic site and once we had the site released to us, Len and I and a few others moved everything from the old site to the new one.

Len set up the web pages that we knew we needed. He moved the graphics and headings and I moved the text, editing and correcting information as we went. We worked night and day to get it ready for the changeover the first week in October.

It cost a lot of money. With only one request that fully explained the situation, the WebWhispers members wrote checks and sent them in freely. We had never asked for this kind of money before, being quite content to volunteer our time. But we had to remind everyone occasionally that we were a non-profit and had no income to stay up and running other than what they gave us.

We opened the new website, put the old site in storage, and opened new features as scheduled. Dutch never saw the new website except for a general design early on.

The last day of 2006, WebWhispers had over 1,300 registered members on our email lists, a new website that was working well, a database that would help us keep our members recorded by types of membership, and a way to print out charts relating to statistics by country and state. We had signed our website into Google Analytics so we could check numbers of visitors to various pages.

Our long time lary member, Len Librizzi, who had been volunteering for years, became our webmaster. He helped us set up the new forms and charts and we configured them to all work together.

A letter went out to our members from Dutch:

Dear Webbies,

My fistula problem is sort of resolved now, but further investigation at MD Anderson revealed that I have rather extensive recurrent cancer about which, for various valid medical reasons, little can be done. It's a situation that presents challenges to not only me, but also to a certain extent to WebWhispers as well. The full story is presented below.

As most of you are aware, I have been dealing with a pharyngocutaneous fistula problem since mid-January 2006.

In late March, I began serious treatment and consultations at MD Anderson Cancer Center in

Houston. I worked with both the Plastic Surgery Clinic and the Head and Neck Surgery Department, and my primary physician was Dr. Weber, the Chief of Head and Neck Surgery. I underwent numerous tests, evals, exams, CT Scans, PET Scans, and radiological and chemotherapeutic consults all during April and May. Throughout the entire process I received nothing but excellent care from probably the best, most knowledgeable, and most caring and courteous cancer-specialized medical staff in the country. They left no stone unturned and my Mazda Tribute SUV learned to make the round-trip drive between El Lago and the MD Anderson campus almost unassisted. (Amazingly, on most days, I managed to avoid the infamous Houston rush-hour traffic, thus road-rage was also avoided almost completely!)

I had the anticipated "Come To Jesus" appointment this past Tuesday with the doctor. It was scheduled for 11:30am and in IAW general hospital tradition, I finally got into see him around 1:30 PM. All the evals, exams, and tests had now been done, so this appointment was to discuss the findings and recommendations to bring everything together in the Big Picture.

First, the general "fistula" problem. Due to the poor condition of the tissues in and around the fistula itself, it was found to be inoperable and untreatable, thus it shall remain with me as is. All I can do is to continue to cover it appropriately with

tape and cotton padding and will be using my PEG tube (stomach feeding tube) to take liquid food and drink for the rest of my life. In short, the fistula cannot be repaired/closed, period. The bottom line is no more Thin-N-Crispy Sausage Lover's Pizzas w/ extra Cheese and Sauce. Just a lot of water, Boost, Ensure, and ProBalance injected through the PEG tube into my stomach. (I will have to content myself with watching the Rachael Ray shows on the Food Channel.)

Second, there are signs of active recurrent cancer in and around the fistula site and in a few other locations within the neck tissues, and indications of a spread to one lung. When this recurrence began is anyone's guess, although the evidence points to late 2004 when I first started to have swallowing problems and problems speaking effectively via my TEP/prosthesis. In 2005, an esophageal stricture had clearly developed between the TEP site and the base of my tongue and so in 2005, I underwent six esophageal dilations (each about 60 days apart) to try to permanently open this stricture. These fixes were only temporary in duration, however, the several biopsies in that area during 2005 did not reveal any active recurrent cancer.

The fistula opened in early 2006 and an attempt was made in January to close it surgically. This was unsuccessful but again, no recurrent cancer was discovered or indicated. This

impression, however, changed during the extensive evals and tests at MD Anderson.

In short, what MD Anderson discovered was that recurrent cancer was indeed there. And probably due to my previous radiation (and the tissue damage done by those treatments in 1993), this recurrent cancer cannot be treated by more radiation in that same area. Additionally, meaningful surgery is not an option, nor is meaningful chemotherapy due to the poor tissue conditions in the proposed surgery sites. In short, the recurrence is there, but nothing can be realistically done except for pain management and palliative care. I am already working with MD Anderson's Pain Management Clinic and so far, so good. I am now on a combination of hydrocodone liquid and fentanyl transdermal patches. These meds control the pain (primarily in the neck and shoulders), which did not really begin or become noticeable until mid/late April of this year. I now wear the patch all the time, changing it every three days; this is supplemented by the Hydrocodone.

Third, the prognosis. Since nothing can be done, it is apparent that the condition is terminal, eventually. Neither the doctor nor his staff were prepared to give me any estimate as to when. It is too complex with too many unknowns. Things could go quickly due to a sudden hemorrhage or a similar tissue failure, or things could move very slowly

over months and months, just a slow deterioration over time. They simply do not know and cannot predict. Their only plan now is to see me again in about sixty days for another CT scan at that time. It is foreseen that, at some point downstream, I would likely enroll in an outpatient hospice program with eventual placement in an inpatient hospice program, using a hospice program of my choice, if or when appropriate.

Fourth, HOW AM I DOING? Well, physically, I have verified recurrent cancer and am in some pain but the pain is under control, thanks to the medication. Again, physically, I would estimate that I now can function at about the 80% level, most of the time. Mentally, psychologically, and emotionally, I am fine. Nothing said last Tuesday came as a real surprise. I was fully prepared to receive and accept this news and am truly thankful for everything MD Anderson has done. I have no complaints. I now will simply play my cards day-by-day and see how things go, doing what I can, when I can, how I can, and for as long as I can. My biggest disappointment is no more great food or drink! I sure will miss eating, drinking, and tasting!

Being single, a Virgo, and an ex-military guy, my personal stuff is relatively straight forward and fully organized and in order. Anything that could have been reasonably pre-planned, pre-arranged, and pre-paid has been accomplished for some time now. My best friend for the last fifty years, who is

also my executor and the holder of my general and medical powers of attorney, lives with his family but one mile away so for those things, all is well.

As for WebWhispers, the other officers are fully informed and up to speed. We all have had contingency plans set up amongst ourselves to cover such eventualities, with lists of things to do should something happen to one or more of us. WebWhispers is and will be fine. Obviously, I will gradually divest myself of many of my long-standing WW duties and responsibilities and pass them off to others. We have already begun to expand the number of qualified moderators available to serve us effectively with the email lists, and the executive committee is already looking seriously at a possible major redesign and restructuring of the web site itself, one less dependent upon a single webmaster and with more people eventually involved in the web site's management, maintenance, and editing processes. Over time and in an orderly process, I will also ease out of my webmaster responsibilities, eventually turning them all over to others who can and will carry on the WebWhispers mission in the WebWhispers tradition. I only ask that, if your WW officers ask for your help or assistance with any of these tasks, you'll find some way to help out if you possibly can.

Now you know what I know and what the other WW officers know. Obviously, there are many

questions you might have that neither I nor they can yet answer adequately. But these will all get sorted out over time. Fellow WW Officers Pat Sanders, Terry Duga, and Libby Fitzgerald are now on the WW 2006 Alaskan tour/cruise and will be discussing the WW's future options a lot while on that trip. When they get back, we will pick up the continuing discussions with the other officers. But the bottom line is that WebWhispers will be taken care of. It is and will remain in good hands.

Thanks for listening and thanks for all the kindness, prayers, and support. There is no need to bury my mailbox (or especially the general WW email lists) with good wishes or positive thoughts. I already know how you are likely feeling. Plus, I still plan to be around for quite a while yet. However, if you do feel the need, please send them to me directly and privately at my personal email.

I wanted to give you all the news and to let you know as best I can tell you what is up and why. Thanks again, and God bless you all!

'Til later!

Dutch

Timewise, Dutch was further along than the membership knew, and even though he might have wished to make it to Chicago, his symptoms were worse as each day went by.

By July, Dutch was in no shape to make the anticipated trip to the IAL, and the WW dinner program held there was used to honor him. We planned for a special table to be set up with many pictures from the past years' events, and a special award to be presented. This award was etched in glass with the WebWhispers logo, his name as our founder, and reads, "Your Legacy Will Continue To Honor You - 2006." He received it while still aware enough to appreciate it and kept it nearby. This award now sits in my window where the sun highlights it and reminds me of what a great experience it was to have had the opportunity to work with this dedicated, intelligent, and inspiring man. To be his friend was an honor.

Dutch was in the hospital by early August and when he left the hospital he never went home again. He went to the home of long-time friends, Mike and Pam, where they cared for him. They were the same friends who took him to live with them after his initial surgery.

He was able to be up some, to sit on their patio, and even though he had his computer there, his messages stopped in early August. On September 1st, Mike wrote with requests from Dutch for me to remove his email addresses from management and from the lists, since he was not reading any of them. After that, I received forwards of emails sent to him that needed to be handled or answered. Mike sent them without being asked.

In early October, the hospice people and Dutch's caregivers thought the end was near. By late October, he was in a coma state. Mike wrote to tell me that the hospice nurse thought there was something holding him here that was unfinished. I wrote a message for them to

read since they thought he might be able to hear. On Oct 28th, Mike called and asked me to talk to Dutch as he held the telephone to his ear. I did, and told him that his creation, WebWhispers, was okay. The new website was working and new members were coming in. I talked about the people and told him, "Everyone asks about you and misses you, and you have more prayers than heaven can hold. We have preserved your old website in the founder's section of the new one, along with some other information from your wonderful history. You will not be forgotten. We want you looking over our shoulders out there in cyber space. Go in peace. We love you." He died in the early morning on November 1st.

WebWhispers Today

We would lose members from time to time, not only to death but to prolonged illness, and not always related to cancer. Many of our newer members were younger and wanted to go back to their work, so were very interested in voice advice and newer items to help them speak clearly enough to hold their old jobs. Sometimes we lost those members, not because they didn't want to be a member, but because they were doing well back out in the real world and just didn't have time to read or participate in the exchange of messages. They knew where to find us if they had a problem or a question. Many of these members were able to go out and be active because of what they learned from our WW Library, experiences shared by other members, and support from these friends.

We were averaging a new member a day and had a steady gain in membership. We have always run on a tight budget with a volunteer staff, but we had started a few small programs for encouragement and support.

One of our new services was to give a small award if any laryngectomee member would attend the Voice Institute, also attended by SLP students, held at the International Association of Laryngectomees Annual Meeting. We knew that WebWhispers members who became more educated in the anatomy, types of surgery, methods of speaking, and types of voices available would be better able to answer other members' basic questions. The Voice Institute is organized and taught by top professionals from around the country and any

laryngectomee's life can be improved by what is learned there in the general classes and the sessions devoted to individuals.

This was funded from the WebWhispers general fund plus donations such as a $1200 donation from Atos Medical. In 2006, the Edmund and Lillian Lauder Laryngectomee Support Fund, sponsored and underwritten by Lauder Enterprises, offered to fully sponsor this program for continuing education annually. There is a section under Services on our WebWhispers.org website that describes exactly how this program works.

We have a new Awards page, which has several other awards that are aimed at helping members with some of the expenses involved in attending the IAL Annual Meeting or Voice Institute. Thanks to InHealth Technologies, the Dutch Helms Travel Grant was set up immediately after his death as an annual award. We will add to or change these programs on occasion, but a visit to our site will tell you the current status.

WebWhispers was started with nothing and has existed on very little with the help of some hard working volunteers who often open their own pockets to give. We have no corporations regularly sponsoring us and exist on mostly small donations. Our records are public and anyone is welcome to look at what it costs us to run the organization.

WebWhispers
Acknowledgments:
The People Who Made It Happen

We were lucky to have Terry Duga from Indianapolis, who was able to form an organization and file the papers of incorporation. We had to have officers and Dutch did not want to be president, which would have been automatic, but he was willing to be VP and webmaster. Our first president was Joe Casey, a fine man who had a knack for melding people into a unit. One of our women laryngectomees became secretary, and Terry Duga accepted the treasurer's job. Besides setting up some basic bookkeeping, he also applied for a 501(c)(3) so that contributions would be tax deductible. I did not want to be an officer, but asked if I could head up the Helpful Hints section. The goal was to build it around the hints and ideas written in the list, ones sent in to us by our members, or those gathered from my HeadLines newsletter that I had been editing for well over two years.

Unfortunately, we lost Joe Casey to the recurrence of cancer toward the end of 1999. We had already learned that he would have made us a marvelous leader through the years, but his death was no surprise. We were aware that he was undergoing treatment for a recurrence. We were fortunate to have had him for the early days of WebWhispers. The president of an organization has such an influence on the direction it takes that the death of Joe Casey impacted our plans for the future.

The vice president, Carter Cooper, became our

second president. He was young, strong, had a busy job, and dove into being our president with enthusiasm. He was determined to make us a bigger organization, one that could successfully apply for grants and support charitable gifts and programs. He had contacts in the field and in early 2000, intended to have a planning meeting to get more information on how to proceed. We needed a good WW turnout at the upcoming IAL Annual Meeting in Nashville that year, and Carter was working on that. Murray Allan, of Richmond, British Columbia, became Carter's vice president.

On July 9, 2000, Carter died due to a massive and instantly fatal heart attack. Everyone was stunned. Murray automatically became president only six weeks after he had accepted the position of VP. As president, he asked me to be his VP. I wasn't sure about taking on that task.

I had been very hesitant about either job in the past and had been asked to run for both. I did a lot of work for WW at different times and loved working with the hints. I accepted the offer to be VP because I knew elections were coming along in a few months and we needed to get past that immediate vacancy.

Murray was the third president in a year, and we needed stability. That was the start of six years with the same president and vice president, and the beginning of the continuity we needed so we could concentrate on the rapid growth we were achieving in both our membership and our services.

Epilogue

Currently, as we are getting ready for publication, I have more than a year left in my present term of office and have served as WebWhispers' president for over seven years. We are still finding new ways of teaching rehabilitation and of furnishing our members and the public with the latest developments. The world of the Internet has been a tremendous source for this but the world of laryngectomees has taught us what is not in books or your doctor's training.

Personally, I am going into my twentieth year as a laryngectomee and I am comfortable with my situation. I seldom think about the inconveniences of the after-effects of the surgery and treatment. If I gave that much thought, I should also note that I no longer get the horrid sinus and bronchial infections twice a year. They gradually went away. I went from taking antibiotics twice a year to needing them twice in five years. The last two times I took them were not even for respiratory problems but I had to have a toenail removed and I had a small wound on my leg. Each time it was taken as preventive medicine. I am in better general health since I became a laryngectomy.

I was asked this morning about why I didn't use the word "survivor" in the book. I don't think I have survived cancer in that way. I lived through having cancer in my body and now I am living without active cancer, but I always live with the possibility of it. Cancer can be a life changing experience and if you are wise, you let it become a good change and make a great life. Don't live

in the past and think how you long to be back there. You don't get to make that U-turn.

If you're thinking that you, a friend, or a member of your family may have cancer of the throat area, I would highly recommend you do not go to the same ENT who treated your child's tonsils and ear infections. You need a doctor who knows what cancer looks like and who works with it. Look at the nearest university teaching hospital with an otolaryngology department. They have the knowledge and the equipment to give you a more accurate assessment of your situation. You need to know if you have laryngeal or esophageal damage or nodules starting and be helped to make the right decision, which may be as simple as taking a pill a day for acid reflux. Let an expert be the one to look down your throat.

If you do have cancer or are caring for someone who does, please come to the WebWhispers.org site and read the library section for information you will need. Join the group so you can write emails and get answers or ideas from others, along with their understanding. Registered members to the site can also access all of the archives, which contains a lot of information from our founder and our members, especially information they learned over the years of this shared experience.

If you have a laryngectomy, it is not the end of the world. But it is the beginning of a different world, and you need to learn about it. We can help you do that.